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**The romantic and sexual lives of adults with
Intellectual Disabilities: Exploring the perceptions
and experiences of mothers and staff using
Interpretative Phenomenological Analysis and
Thematic Synthesis.**

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Doctorate in Clinical Psychology
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April 2020

Declaration of Own Work

Name: Maria Charitou

Title of Work: The romantic and sexual lives of adults with an Intellectual Disabilities:

Exploring the perceptions and experiences of mothers and staff using Interpretative

Phenomenological Analysis and Thematic Synthesis.

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Date 21st April 2020

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Thesis Abstract

Research has evidenced that individuals with Intellectual Disabilities (ID) value and desire romantic and sexual relationships, however often lack the opportunities and socio-sexual knowledge required to pursue these. In this context, family and staff play a key role in enabling individuals with ID to fulfill their sexual and romantic needs. In recent years this has led to a growing body of research focusing on how family carers and staff perceive the romantic and sexual lives of individuals with ID and their own role in supporting these.

Given the available qualitative literature focusing on staff experiences of supporting the sexuality and relationships of individuals with ID, a systematic review was conducted to explore, collate and critically appraise qualitative research in this area. Findings from included studies were analysed using thematic synthesis. Four themes were identified: (a) “Attitudes towards sexuality and relationships: A right and a challenge”, (b) “Responding to sexuality and relationships: A conflicted discourse”, (c) “Uncertainty and lack of systemic support”, and (d) “Influences on decision-making”. These findings are discussed alongside existing literature and are used to make recommendations for research and practice.

Most previous research with parents has primarily focused on parental perceptions of their children’s emerging sexuality during adolescence, as opposed to perceptions of their wider romantic and sexual experiences as they grow older. This study explored the experiences of nine mothers of adult individuals (18-41 years old) with mild/moderate ID regarding their sons’ and daughters’ romantic and sexual lives using interviews. Data was analysed using Interpretative Phenomenological Analysis (IPA) and organised into five themes: (a) “Just like everybody else”, (b) “But is it really the same?”, (c) “Risk and vulnerability”, (d) “Facilitating and protecting: A fine balance” and (e) “Exploring personal meaning and hope”. The findings emphasised the need for supporting mothers in their role, especially in relation to providing sexual education to their children. Suggestions for future research are discussed.

Thesis Lay Summary

Research has shown that individuals with Intellectual Disabilities (ID) value and desire romantic and sexual relationships, however they often have limited opportunities and knowledge to develop these. Family carers and staff can be a valuable source of support and guidance for individuals with ID and can help them fulfill their sexual and romantic needs. Several studies have been carried out in order to explore how parents and staff view and experience their role in helping individuals with ID with relationships and sex.

A systematic review was conducted in order to review the quality of qualitative studies on the experiences of staff in relation to supporting the sexuality and relationships of individuals with ID. The findings of these studies were collated using thematic synthesis, which revealed four main themes: (a) “Attitudes towards sexuality and relationships: A right and a challenge”, (b) “Responding to sexuality and relationships: A conflicted discourse”, (c) “Uncertainty and lack of systemic support”, and (d) “Influences on decision-making”. These findings are discussed in the context of previous research and are used to make recommendations for practice and future research.

Our understanding of how parents view and experience the romantic and sexual relationships of their sons and daughters, especially as they grow older, is limited. In order to increase our knowledge in this area, nine mothers of adult individuals (18-41 years old) with mild/moderate ID were interviewed about their adult children’s romantic and sexual lives. Their interviews were recorded, transcribed and analysed. Five main themes were found to be important amongst mothers’ narratives: (a) “Just like everybody else”, (b) “But is it really the same?”, (c) “Risk and vulnerability”, (d) “Facilitating and protecting: A fine balance” and (e) “Exploring personal meaning and hope”. These results suggest that mothers need support in their role, especially in relation to helping their sons and daughters with sexual matters. Suggestions for future studies in this area are discussed and recommendations for practice are made.

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Journal Article 1: Systematic Review

Supporting adults with Intellectual Disabilities with relationships and sex: A systematic review and thematic synthesis of qualitative research with staff.

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Written in accordance with submission guidelines for Sexuality and Disability (See Appendix 1 for author guidelines).

1. Abstract

Background: Staff working with individuals with Intellectual Disabilities (ID) play an important role in enabling them to fulfill their sexual and romantic needs. Given the lack of recent reviews providing a synthesis of qualitative research in this population, the present review aimed to explore how staff, working with individuals with ID in a variety of capacities, perceive and experience their role in relation to supporting sexuality and relationships. *Methods:* A systematic search of EMBASE, PsychINFO, MEDLINE, CINAHL, ASSIA and SCOPUS was carried out and identified articles were rated against inclusion and exclusion criteria, as well as quality criteria. Findings were analysed using thematic synthesis. *Results:* The application of criteria resulted in the inclusion of 15 articles. Four analytic themes were identified: (a) “Attitudes towards sexuality and relationships: A right and a challenge”, (b) “Responding to sexuality and relationships: A conflicted discourse”, (c) “Uncertainty and lack of systemic support”, and (d) “Influences on decision-making”. *Discussion:* The findings suggest that staff hold ambivalent attitudes and often respond in an avoidant or inconsistent manner to the sexuality of service users. Role uncertainty, fear of accountability, and lack of training and policy were identified as barriers. Factors related to employing organisations, family caregivers and service users themselves were found to influence decision-making. Limitations, implications for practice and suggestions for future research are discussed.

Keywords: Intellectual Disabilities, staff, sexuality, relationships, qualitative, synthesis.

Word Count: 13, 877

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2. Introduction

The previous decades have witnessed significant legislative and societal changes to the rights of individuals with Intellectual Disabilities (ID) including education, employment and social inclusion [1]. Although it is well established in the literature that individuals with ID have sexual needs and value relationships [2], the area of relationships and sexuality has not been at the forefront of the social inclusion agenda [3] and has only attracted attention in recent years. In the United Kingdom, policies such as “Valuing People” have emphasised the importance of relationships and sexual health for individuals with ID [4]. Research however, suggests that policy implementation is not always straightforward and as a result, the romantic and sexual lives of individuals with ID often remain unfulfilled and with fewer opportunities than their non-intellectually disabled counterparts [5].

In the United Kingdom, the implementation of de-institutionalisation policies [6] has led to individuals with ID being supported by a wider range of community workers. This often includes direct support staff in supported accommodation and community services (e.g. advocacy organisations), as well as health and social care professionals. Individuals supporting people with ID in any professional capacity can influence their ability and opportunities to engage in romantic and sexual relationships. For example, individuals with ID tend to have limited social networks [7] and reportedly display poor knowledge on issues related to relationships, sexuality and sexual health [8]. As such, they often rely on support staff and professionals for emotional and practical support [7], as well as for guidance on issues relating to sexuality specifically [9,10]. Support staff can also directly influence service users’ opportunities to pursue relationships, for example by determining the availability of private spaces in their environments or by imposing restrictions to social interactions [2, 11].

Attitudinal research in this area suggests that staff generally tend to hold moderately liberal attitudes towards the romantic relationships and sexuality of individuals with ID [12-15]. It should be noted, however, that such findings may be context-specific as there is some evidence to suggest that staff employed in inpatient settings demonstrate more conservative attitudes compared to those employed in community settings [16, 17]. Furthermore, findings of research in this area could be compromised by the use of self-report questionnaires, which can add a degree of self-report bias [18]. Some studies have found that staff of younger age tend to hold more liberal attitudes [10, 12], however other studies have failed to identify age related differences [15]. More positive attitudes have also been linked to higher education level [12, 19] as well as to having received previous training in sexuality and having an understanding of relevant service policy [17, 20]. Limited evidence would also suggest that specific aspects of relationships and sexuality such as parenthood or homosexuality may attract more conservative attitudes [12, 17].

In recent years, a growing body of qualitative research has emerged in this field with the aim of exploring the experiences of staff in relation to supporting individuals with ID with relationships and sex. Although qualitative studies can complement existing quantitative research by exploring complex phenomena in more depth [21], a frequent concern is that such studies often become marginalised and are rarely used to influence practice and drive change [22]. In this context and to alleviate this concern, reviews and syntheses of qualitative research can be valuable in providing knowledge with depth, due to the use of qualitative designs, and breadth, by drawing together data from different studies and contexts [23]. Furthermore, the synthesis of qualitative research can draw attention to underlying processes not highlighted by individual studies, illuminate future research directions and facilitate the transfer of a volume of knowledge to inform practice [24].

Three reviews of qualitative research on staff experiences in relation to the romantic and sexual relationships of individuals with ID have been published to date [11, 25, 26]. In 2014, Rushbrooke and her colleagues [11] used meta-ethnography to review and synthesise the findings of 17 qualitative studies exploring the difficulties faced by paid (staff) and unpaid (family) caregivers in relation to the sexuality of individuals with ID. Chrastina and Večeřová [25] also conducted a brief review of both qualitative and quantitative studies exploring the issue of support for adults with ID in relation to sexuality from the perspective of individuals with ID themselves, close persons, carers, and staff. More recently, Brown and McCann [26] conducted a review and narrative synthesis of mixed literature, including seven qualitative studies, on the views and experiences of family caregivers and direct support staff (i.e. support workers) in relation to the sexuality of individuals with ID.

The findings of the aforementioned reviews suggested that paid caregivers held diverse views on the sexuality of individuals with ID [11, 25, 26] and their personal experiences and values impacted on their perceptions of sexuality [11]. Sexuality was generally described as a right, however it was often talked about as conditional upon certain factors [11] and as a source of risk due to the possibility of abuse and exploitation [11, 26]. All three studies also highlighted a conflict between paid caregivers' desire to support sexual expression for individuals with ID whilst protecting them from risk, which on some occasions arose from the use of the Internet and new technologies [26]. Two reviews highlighted that paid caregivers reported confusion regarding their role, lack of training and uncertainty surrounding service policy on ethically challenging topics such as that of sexuality [11, 26]. This in some occasions led to high levels of anxiety for paid caregivers as well as to inconsistent responses to issues of sexuality based on 'unwritten' rules [11]. In this context, a need for development of policy and training opportunities for staff was emphasised in order for staff to be in a position to support service users with issues relating to sexuality [11, 25, 26].

3. Rationale for the Current Review

Although the findings of the existing published reviews are valuable, they suffer from certain limitations. For example, as Chrastina and Večeřová [25] did not carry out a quality appraisal of included articles or a systematic synthesis of previous research, their findings provide only limited information regarding the quality and content of included research. Furthermore, due to the inclusion of mixed methods literature, the narrative review conducted by Brown and McCann [26] did not provide a qualitative synthesis of previous findings to allow for a more in depth reflection of staff experiences. Additionally, as Brown and McCann [26] only included research conducted with direct care staff, findings from studies concerned with the experiences of other professional groups such as nurses, clinicians or educators were not illuminated. Another possible limitation of the existing three reviews is their broad focus on both paid and unpaid (family) caregivers, which has perhaps not allowed for the unique barriers faced by each caregiver group to be illuminated separately and in sufficient depth.

In addition, since the publication of all three reviews, a number of qualitative research studies concerned with staff experiences in relation to their role of supporting the sexuality of adults with ID have been published [27-32]. In their discussion regarding the necessity of updating qualitative systematic reviews, France and colleagues [33] concluded that the emergence of new research, potentially contributing novel concepts, warrants an update. As such, the present review aimed to provide an updated quality review and synthesis of existing qualitative research, including more recent literature. In addition, considering that a limitation of previous reviews and syntheses was their lack of specific focus on paid caregivers as well as a focus on a single professional group (i.e. support workers), the current review aimed to provide a more focused representation of available research on the experiences and views of staff employed in a variety of capacities.

4. Method

4.1. Inclusion and Exclusion Criteria

Studies eligible for inclusion met the following criteria: a) they were published primary research written in English and published up until October 2019, b) employed a qualitative design or mixed methods design where the qualitative results were accessible and c) focused on exploring how direct staff and professionals perceived the romantic and sexual needs of adults (over 18) with ID and supported them with romantic relationships and relational aspects of sexuality (intimacy, sexual knowledge, safety, contraception). Exclusion criteria included studies with a focus on: a) medical aspects of sexual health (e.g. penile hygiene, HIV prevention), b) risk reduction (e.g. sexually challenging/offending behaviour, sexual abuse, sexuality in forensic settings) and c) sexual education programme evaluation. Due to the heterogeneity of the staff groups involved in existing research, in this review the term “staff” was used to describe a range of direct support staff and professionals (e.g. support workers, clinicians, nursing staff, educators, managers etc.). Similarly, as the majority of studies did not specify the severity of the ID of the service users supported, the term “ID” was used to cover presentations ranging from mild to severe as per categorisation using the ICD-10 [34] and DSM-V [35] systems.

4.2. Search Strategy

Search terms were developed through a review of the literature and discussion with an experienced librarian. These were as follows: *(learning OR intellectual*) AND (disab* OR disorder* OR “mental retard*” OR “mentally retard”*) AND (attitude* OR belief* OR experience* OR understand* OR percep* OR view* OR interview* OR know* OR opinion*) AND (personnel OR staff OR clinician* OR profess* OR “support work”*) AND (romance OR romantic* OR relationship* OR sex* OR intima* OR love)*. Using the identified search terms, the main researcher conducted a systematic electronic search in October 2019. The following

six electronic databases were searched; EMBASE, PsychINFO, MEDLINE, CINAHL, ASSIA and SCOPUS. It has been acknowledged that the successful identification of qualitative research through database searches depends on the quality and clarity of research titles and abstracts, as well as on the database indexing practices [36]. In order to reduce the risk of omitting studies relevant to the topic of review, the main researcher carried out an additional hand search of reference lists of included papers and a manual search of Google Scholar and key journals.

4.3. Data Extraction

Descriptive information and summaries of main findings were extracted from each out of the 16 selected papers into a table by the main author (i.e. see Table 2). The following information was extracted: (a) the names of the main authors, (b) the focus of the study, (c) the country of origin, (d) the number and type of participants involved, (e) the method and type of analysis used and (f) a summary of qualitative findings.

4.4. Quality Appraisal

The growing recognition of qualitative research as having the potential to valuably contribute to evidence-based practice has led to the development of methods aimed at critically appraising its quality [37]. This is particularly relevant when conducting systematic reviews, as their overall quality partly depends on the quality of included articles [38]. In the present review, the quality of all included studies was assessed using the Critical Appraisal Skills Programme (CASP) qualitative tool [39], a copy of which can be found in Appendix 2. The CASP provides a ten-question checklist-based framework for assessing the quality and rigour of selected studies and is widely used for the purposes of the quality appraisal of qualitative research [40]. In order to enhance rigour and minimise the potential for error, a second researcher independently reviewed a randomly selected number of papers using the same

quality criteria. As CASP does not provide a system according to which ratings can be categorised, for the purposes of the present study the numerical scoring system and global quality ratings introduced by Butler, Hall and Copnell [41] were utilised in order to facilitate the comparison of ratings between the two raters. Based on their performance against the CASP criteria, articles were assigned ratings of “low”, “moderate” and “high”.

4.5. Synthesis of Findings

In a recent publication of the Cochrane Qualitative and Implementation Methods Guidance, Noyes and colleagues [40] reviewed thematic synthesis [42], framework synthesis [43] and meta-ethnography [44] as the most commonly used approaches for qualitative evidence synthesis. They concluded that thematic synthesis was the most accessible and clear method of analysis, followed by framework synthesis, whereas meta-ethnography required more caution in its use due to its complex methodology and unsatisfactory current reporting guidelines. Accordingly, meta-ethnography was not considered a suitable approach for the purposes of the present study. Although framework synthesis, which involves the identification of a framework against which data is organised [43], was initially considered, no suitable conceptual framework could be identified from relevant theory. This approach was therefore not considered suitable, as in the absence of a justified a priori framework, there is a risk of data being simplistically forced into a framework [40].

With the above considerations in mind, thematic synthesis was selected as the preferred method of data synthesis. The process of thematic synthesis involved the three steps proposed by Thomas and Harden [42]; free line-by-line coding of text to produce free codes and identify key concepts, organisation of free codes into descriptive themes and development of broader analytical themes. In line with the recommendation of Thomas and Harden [42], the coding process included data labeled as “results” or “findings” and referred to both verbatim quotes and themes identified by authors. The process of coding for each

paper led to the production of a bank of codes. On the basis of their similarities and differences, as well as identified relationships between codes, these were arranged into descriptive themes through a process of assimilation and creation of new themes when necessary. The final step involved the development of higher-order analytical themes, which sufficiently reflected and explained the subthemes as a whole.

4.6. Researcher Reflexivity

The value of remaining mindful of potential prior beliefs or prejudices that could impact on data interpretation when reviewing research has been highlighted in the literature [40]. Although such influences cannot and should not be entirely eliminated, a commitment to reflexivity ensures that they are being accounted for [45]. While conducting the present review, the main researcher was concurrently investigating the perceptions and experiences of mothers of individuals with ID in relation to their children's romantic and sexual lives. As a result, this may have impacted on the present synthesis in terms of what areas were focused on or perceived as important. Nevertheless, the main researcher remained mindful of this potential influence and took steps in order to maintain her subjectivity during analysis, for example by temporarily distancing herself from her ongoing primary research and continually checking themes produced by the analysis against the original papers to ensure they remained reflective of the dataset.

5. Results

5.1. Screening Process

The screening process involved the stages recommended by the Preferred Reporting Items for Systematic Reviews (PRISMA) protocol [46]. These are diagrammatically displayed in Figure 1. An initial search across all databases yielded 8,117 records, which were exported to Mendeley software to facilitate screening and de-duplication. After removing duplicates, a

total of 4,732 records were screened for relevance and out of these, 4,651 records were excluded on the basis of their titles and/or abstracts. When an abstract was not descriptive enough, the full text was screened. A remaining 81 records were reviewed in full text to determine their eligibility. During this process the main researcher contacted a number of authors to establish the publication status of identified papers (e.g. abstracts published in conference proceedings) and these were retrieved in full-text where possible.

Following full text review, 13 records were deemed eligible and 64 records were excluded on the grounds of exclusion criteria. A summary of excluded articles with reasons can be found in Appendix 3. Four further records were identified through the main authors' manual search of key journals and Google Scholar, leading to a total of 17 articles. Further review of the 17 articles revealed that two of the selected papers [27, 28], were separate publications originating from the same primary research. Although these had a somewhat different focus, a review of their content indicated that there was a significant degree of overlap. As one of these two articles [27] provided a richer description of concepts represented in both studies, a decision was made to retain only that article.

5.2. Quality Assessment

For the purposes of quality assessment, the main author carried out quality ratings and a second reviewer independently completed ratings for a random sample of 50% of included papers to verify inter-rater reliability. This process indicated 86% inter-reviewer agreement. The kappa coefficient was calculated to account for the probability of agreement occurring on chance alone and the calculated value ($K = .67$, 95% CI [0.36-0.99]) suggested an adequate level of agreement [47]. In instances where there were disagreements in ratings, these were resolved through discussion. Assigned scores and global ratings are illustrated in Table 1.

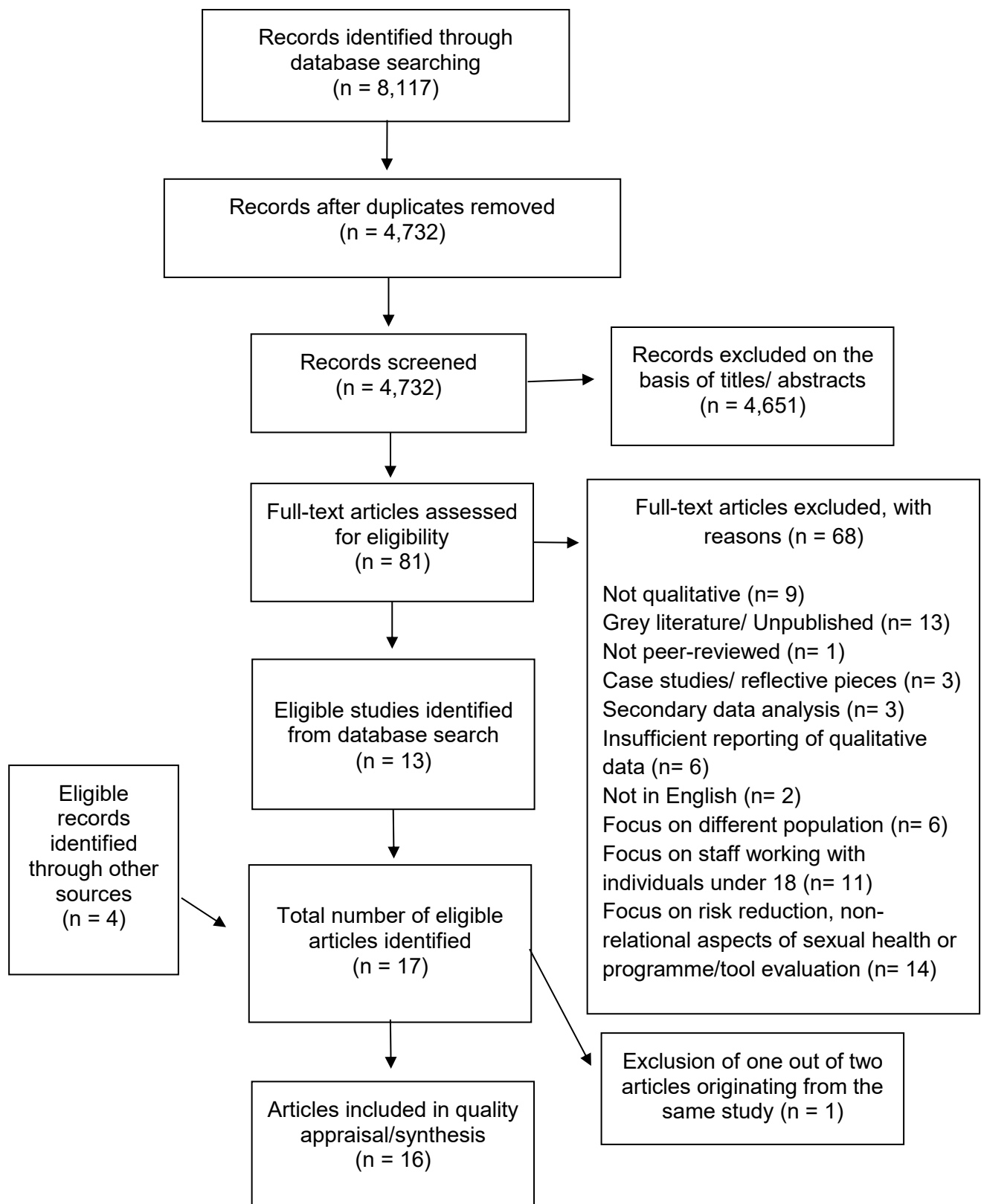


Figure 1: Search Process Flowchart based on the PRISMA Group [46]

Five studies received “high” global quality ratings [27, 31, 32, 48, 49], nine received “moderate” global quality ratings [29, 50-57] and two received “low” global quality ratings [30, 58]. Low ratings were most commonly attributed to limited information provided in relation to ethics procedures followed and consideration of the researchers’ role and its impact on the planning and conducting of research. Another area in which a number of studies achieved low scores was that of analysis, most commonly due to the insufficient reporting of the stages and process of analyses carried out.

In their proposed scoring system, Butler and colleagues [41] recommend that studies scoring less than six be excluded from reviews. In this review, one study [58] achieved a score of five, predominantly due to insufficient reporting of the research aims, recruitment, data collection, researcher role, ethics and process of analysis. There is much debate in relation to whether quality appraisal should determine inclusion or exclusion of articles [59]. Some authors have argued that the inclusion of low quality articles can distort the findings of a review and subsequently its overall credibility [60]. Other authors have proposed that the impact of excluding poorly reported studies on the depth and thickness of a review’s overall findings is sometimes minimal due to the often limited contribution of poorly reported studies [61], therefore making a case for their exclusion. Although it is acknowledged that the use of a numerical threshold as a cut-off criterion has its limitations [59] and that low scores can be reflective of poorly reported as opposed to poorly conducted research [62], in the present review quality ratings determined inclusion and exclusion. A decision was therefore made to exclude the article by Hamilton and colleagues [58]. The exclusion of articles receiving low quality ratings from synthesis is also consistent with previous syntheses in this subject area [11].

Table 1: Quality Ratings Table

	Quality Criteria											
Articles (First Author & Year)	(1) Aim	(2) Methods	(3) Design	(4) Recruitment	(5) Data Collection	(6) Researcher role	(7) Ethics	(8) Analysis	(9) Findings	(10) Value	Total Score	Global Rating
Abbot (2007)	0.5	1	1	1	1	0.5	0	1	1	1	8	Mod
Cwirynkalo (2017)	1	1	1	0.5	1	0.5	0.5	0.5	1	1	8	Mod
Hamilton (2002)	0.5	1	1	0.5	0.5	0	0	0	1	0.5	5	Exc.
Höglund (2019a)	1	1	1	0.5	1	1	1	1	1	1	9.5	High
Lafferty (2012)	1	1	1	1	1	1	1	0.5	1	1	9.5	High
Löfgren-Mårtenson (2015)	1	1	0.5	1	1	1	1	1	1	0.5	9	High
Maguire (2019)	1	1	1	1	1	0	1	0.5	1	1	8.5	Mod
Martino (2019)	1	1	0.5	1	0.5	0	0	1	1	0.5	6.5	Low
Neuman (2019)	1	1	1	0.5	1	0.5	1	1	1	1	9	High
Pariseau-Legault (2017)	1	1	1	0.5	0.5	0.5	1	0.5	1	1	8	Mod
Pariseau-Legault (2019)	1	1	1	1	1	0.5	1	1	1	1	9.5	High
Parkes (2006)	1	1	1	0.5	1	0	0.5	0.5	1	1	7.5	Mod
Saxe (2016)	1	1	1	1	1	0	0	1	1	1	8	Mod
Thompson (2014)	0.5	1	1	1	1	0	1	1	1	1	8.5	Mod
Young (2012)	1	1	0.5	1	1	0	1	0.5	1	1	8	Mod
Wilkenfeld (2011)	1	1	1	1	1	0	1	0.5	1	0.5	8	Mod
Scoring system: Yes- 1 point Unsure- 0.5 points No- 0 points High Quality: Scores 9-10 Low Quality: Less than 7.5 Moderate Quality: Scores 7.5-9 Exclude: Less than 6												

5.3. Characteristics of Included Studies

Extracted information regarding papers included in the review can be found in Table 2. All 15 studies used qualitative methodology; ten used interviews for data collection, three used focus groups, one combined interviews and focus groups and one used a qualitative questionnaire. Of the ten studies that collected data using interviews, seven specified the use of semi-structured interviews, one specified the use of an open-ended structured interview and two did not specify the interview approach. A variety of methods were used for data analysis, including thematic analysis, grounded theory, content analysis, interpretative phenomenological analysis, discourse analysis and methods of analysis drawing from phenomenology. Of the 15 studies included in this review, four were conducted in the United Kingdom, four in Canada and two in Sweden. The remaining five were conducted in Australia, Poland, Northern Ireland, Israel and the United States.

A total number of 297 staff participated across studies. This included 129 support workers, 13 educators, 19 midwives, eight ID nurses, five social workers, eight ID service managers and 115 professionals from unspecified mixed backgrounds, such as nurses, support workers, educators, psychologists and clinicians. Some of the included studies collected data from staff as well as other populations, such as family carers or service users [48, 49, 55]. For the purposes of this review, only data collected from staff was included in the analysis. One study [57] included in their sample educators working with individuals under the age of 18. However, as their views were presented separately from those working with older individuals and differences between groups were discussed, data from participants working with the older age group was included.

Table 2. Summary of Included Studies

Author(s) and Year	Focus of Study	Country	Number and Type of Participants	Methods and Type of Analysis	Key Qualitative Findings
Abbott & Howarth (2007)	Staff views on supporting LGBT sexual and intimate relationships.	United Kingdom	71 direct support staff workers and managers employed at range of services including residential community services, day services, a long-stay hospital and advocacy services	Semi-structured interviews Grounded Theory	Staff did not feel confident approaching the issue of sexuality, which was frequently described as an inappropriate topic of discussion unless raised directly by service users or until a “crisis” occurred. The views of parents and carers were described as a barrier to providing support related to sexuality. Staff identified a lack of training regarding sexuality and same-sex relationships, and unfamiliarity with policies.
Cwirynkalo et al. (2017)	Exploration of support staff perspectives in relation to the sexuality of individuals with ID.	Poland	16 support staff workers employed at residential settings and day centres	Semi-structured interviews Phenomenological method	Two conflicting discourses of sexuality as a human right with positive implications and as a problem were identified. Barriers to the sexual expression of individuals with ID resulted from family reactions, public perceptions of disability and lack of systemic support. Personal characteristics of individuals with ID were perceived as potential barriers or facilitators. More systemic support and further education/ training were identified as essential.
Höglund & Larsson (2019a)	Midwives’ ethical dilemmas and legal considerations in relation to contraceptive counseling for women with ID.	Sweden	19 midwives working at antenatal/family planning clinics	Five focus groups Inductive content analysis	Midwives described ethical dilemmas related to women’s vulnerability and risk of abuse. Dilemmas were reported in relation to achieving a balance between supporting women’s autonomy and offering protection or directive support, as well as seeking assistance from supporting persons (e.g. family members). Organisational support was described as insufficient and midwives identified a need for additional support and supervision.
Lafferty et al. (2012)	Exploration of the views of professionals and family carers in relation to barriers to relationships and sexuality education.	Northern Ireland	24 frontline staff workers, 26 family carers and 24 professionals	Focus Groups & Interviews Thematic Content Analysis	There was a recognised need for Relationships and Sexuality Education (RSE), but also an acknowledgement amongst staff that it was not regularly provided and was often reactive in nature. Several barriers to RSE were reported, mainly the need to protect from vulnerability, lack of training, limited resources and cultural restrictions.

Author(s) and Year	Focus of Study	Country	Number and Type of Participants	Methods and Type of Analysis	Key Qualitative Findings
Löfgren-Mårtenson et al. (2015)	Exploration of the perceptions of professionals and parents regarding the use of the Internet for sexual purposes by young people (over 18) with ID.	Sweden	Eight professionals working at secondary schools and five parents	Five semi-structured focus groups Thematic Analysis	Findings highlighted that the Internet was viewed as providing social opportunities that might not be available in real life, but also as exposing individuals with ID to new risks. Professionals emphasised the complexities of young people understanding the rules of conduct when navigating the Internet (e.g. self-exposure, accessing pornography) and discussed the complex nature of who holds responsibility for preventing risks related to the use of the Internet.
Maguire et al. (2019)	Exploration of support workers' perceptions of their role of supporting the sexuality of people with ID.	United Kingdom	Six support workers employed at supported living services	Semi-structured interviews using vignettes. Interpretative Phenomenological Analysis	Participants described performing competing roles as facilitators and protectors. Response to issues relating to sexuality was variable and changeable due to a lack of role clarity and the influence of contextual factors and personal beliefs. Staff perceived their role in response to sexuality as limited and often distanced themselves from responsibility.
Martino & Perreault-Laird (2019)	Exploration of the experiences of direct care workers in relation to the sexuality of people with ID.	Canada	Six direct care workers employed by service agencies and non profit care organisations	Interviews Thematic Analysis	Staff felt unclear about their role in raising the issue of sexuality and at times showed a lack of commitment to their role, as they did not view it as permanent. Staff expressed discomfort raising the issue of sexuality, which led to avoiding the topic, and expressed a belief that this would be against the religious values of their organisation.
Neuman (2019)	Exploration of the attitudes of support staff in relation to the couple relationships of adults with ID.	Israel	40 direct support staff	Semi-structured interviews Thematic Content Analysis	Support staff perceived couple relationships as more challenging for people with ID and described challenges as resulting from the relationships themselves and the actions of others. Desire for involvement in relationships was often attributed to a desire for a more normative lifestyle. Participants generally described their role in relation to supporting couple relationships as limited and often focussed solely on conflict situations.

Author(s) and Year	Focus of Study	Country	Number and Type of Participants	Methods and Type of Analysis	Key Qualitative Findings
Pariseau-Legault & Holmes (2017)	Exploration of staff perspectives on the emotional and sexual expression of individuals with ID, and on the impact of influencing factors.	Canada	16 participants including five service users, six support workers and five parents	Semi-structured interviews Analysis through circular interpretative process and subsequent Foucauldian discourse analysis	Support workers reflected on the complexity of their role and expressed a desire to facilitate the emotional and sexual expression of service users. They reported a lack of clear policies. They described a range of restrictive practices within services and reflected on the need to remain emotionally vigilant and safeguard individuals with ID.
Pariseau-Legault et al. (2019)	Exploration of support workers' experiences in relation to sexuality in the context of ID from an ethical perspective.	Canada	Six support workers employed at a rehabilitation service	Interviews Interpretative Phenomenological Analysis	Findings highlighted that, despite recognition of the value of affective and sexual expression, staff described this as crossing the boundaries of their role and organisational policy. Despite the uncertainty regarding their role, staff expressed a commitment to managing such situations when they arose and their narratives revealed a balancing act between accountability and their duty to meet service users' needs, whilst managing their own personal values and beliefs. Findings highlighted the difficulties of navigating a contradictory discourse, which emphasised participation and autonomy, yet was dominated by a risk management narrative.
Parkes (2006)	Exploration of support staff's perceptions and experiences in relation to the sexuality of service users with ID.	United Kingdom	Nine care staff at day centres	Focus Groups Method as described by Dey (1993)	Participants reported several sexual situations where a response was required however this often relied on personal judgement. Factors identified as barriers included the perceived vulnerability of individuals with ID and parents'/carers' reactions. Participants discussed cases where service users reacted to oppression of their rights and reflected on their own emotional reactions and coping. There was some evidence that same sex relationships may attract homophobic reactions.

Author(s) and Year	Focus of Study	Country	Number and Type of Participants	Methods and Type of Analysis	Key Qualitative Findings
Saxe & Flanagan (2016)	Exploration of how prepared support workers feel to manage sexuality related issues when working with individuals with ID.	Canada	16 University students with previous or current experience as support workers	Open-ended qualitative questions as part of a larger questionnaire Inductive content analysis	Participants reported lack of experience and confidence in dealing with sexuality related issues, as well as lack of clear policy. Those who felt confident attributed this to their work experience rather than training received. Although participants identified protection and teaching service users how to display sexually appropriate behaviours as goals, helping them maintain positive relationships was also identified as a need.
Thompson et al. (2014)	Exploration of the perspectives of clinicians and service managers on barriers to the provision of sexual health services for people with ID.	Australia	Eight disability service managers from government operated and funded organisations 23 clinicians working in same services (psychologist, nurse, educator, counsellor, behaviour specialist)	Semi-structured interviews Grounded Theory	The main barriers identified included lack of policy and training, attitudinal barriers and lack of lifelong sexual health for individuals with ID. Overall, service providers reflected on the barriers as limiting their ability to promote service users' sexual health and leading to sexual behaviours being pathologised.
Young et al. (2012)	Exploration of staff attitudes towards the sexuality of individuals with ID in relation to gender.	United Kingdom	10 staff working directly with people with ID in a variety of capacities at day centres, social services and support agencies	Semi-structured interviews Thematic Analysis	Staff perceived females as more innocent and vulnerable to risk, whereas males were viewed as more driven by biological sexual desires and as more predatory. Different motivations for intimate relationships were assigned to individuals with ID depending on their gender.
Wilkenfeld & Ballan (2011)	Exploration of the beliefs and attitudes of educators towards the sexuality of individuals with ID.	United States	Five teachers in a school based program (for individuals under 18) and five instructors in an adult day services based program (for individuals over 18)	Open ended, structured interviews Content analysis	Educators in adult day services discussed service users' sexuality as a human right and a need that should be supported and promoted. The issue of service users' ability to consent to sexual relationships was raised as a factor influencing the facilitation or prevention of sexual relationships and sexual education was identified as a vehicle through which service users can learn to develop healthy and safe relationships.

5.4. Thematic Synthesis

The process of coding produced a total of 49 codes (Appendix 5). In order to group codes into descriptive themes, similarities and differences were considered and this process yielded a total of eight subordinate descriptive themes. While other methodological approaches that examine the recurrence of themes give clear guidelines regarding the frequency with which themes need to appear across the dataset in order to be considered representative [63], no such guidelines have been explicitly stated for thematic synthesis. As articles included in this review reported relatively consistent findings, all descriptive themes were represented in at least half of the included articles and are therefore likely to be reflective of the dataset as a whole.

Thomas and Harden [42] acknowledge that, although descriptive themes produced from the analysis can be similar to the themes of the original studies, thematic synthesis aims to “go beyond” the content of original studies. This was achieved by using the descriptive themes to address the research questions under review, with an understanding that the creation of more abstract themes would depend on the researcher’s insight and judgment [42]. More specifically, the reviewer inferred the experiences of staff in relation to supporting the sexuality and relationships of individuals with ID in general, and in doing so also considered what factors might be influencing decision-making within their role. Consideration was also paid to staff attitudes and perceptions of their role in supporting sexuality and relationships. This process led to the creation of four abstract and analytical themes, which were refined until they reflected the eleven produced subthemes sufficiently. The final superordinate and subordinate themes are shown in Table 3, alongside contributions from each included article.

Table 3. Superordinate and Subordinate Themes with Article Contributions

Articles (First author & year)	Attitudes towards sexuality and relationships: A right and a challenge		Responding to sexuality and relationships: A conflicted discourse		Uncertainty and lack of systemic support			Influences on decision-making			
	A right and a universal need	A problem and a source of risk	Supporting sexuality and relationships	Keeping sexuality and relationships at a distance	Lack of guidelines and policy	Lack of training and support	Uncertainty about role	Organisa-tional factors	Fear of responsibility and repercussions	Service user factors	The role of family caregivers
Abbot (2007)		X	X	X	X	X		X	X		X
Cwirynkalo (2017)	X	X	X			X	X	X		X	X
Hamilton (2002)	X	X	X		X		X	X	X	X	X
Höglund (2019a)	X	X	X		X	X	X			X	X
Lafferty (2012)	X	X	X	X	X	X	X	X	X	X	X
Löfgren-Mårtenson (2015)	X	X								X	
Maguire (2019)	X	X	X	X	X		X		X	X	
Martino (2019)				X	X	X	X	X	X		X
Neuman (2019)	X	X	X	X						X	X
Pariseau-Legault (2017)		X	X		X		X	X			
Pariseau-Legault (2019)	X	X		X	X	X	X	X	X		X
Parkes (2006)	X	X	X	X	X		X		X		X
Saxe (2016)		X			X	X				X	
Thompson (2014)		X	X	X	X	X	X	X	X	X	X
Young (2012)		X								X	
Wilkenfeld (2011)	X	X	X					X		X	

5.4.1. Attitudes towards sexuality and relationships: A right and a challenge

The majority of included studies found that staff provided a conflicted discourse when reflecting on their attitudes towards the sexuality and relationships of individuals with ID, with their narratives generally portraying romantic and sexual expression as a human right as well as a challenge and a source of risk.

Subtheme 1: A right and a universal need

Staff in nine studies described the sexuality and relationships of individuals with ID as a human right that should be respected and promoted within services and organisations [27, 29-32, 48, 49, 51, 54, 57]. In some cases, there was an acknowledgement that these rights were violated or disrespected, and often this triggered feelings of frustration and anger for staff [49, 51, 54, 57]: *“You know what I mean, I’d hate for anybody to miss out because I think it’s such a wonderful thing. I just feel so frustrated sometimes when I think this is what they want and people are stopping them”* [51, p. 35].

Fewer studies focused on the emotional or social value of relationships in the lives of individuals with ID. Those who did, described involvement in sexual and romantic relationships as not only meeting physical needs, but also as having the potential to meet a range of emotional and social needs for individuals with ID [27, 31, 49, 54, 57]. For example, involvement in relationships was in some cases described as reducing loneliness and giving the individual a sense of shared purpose: *“I’m really in favour of their relationships. They really function better when they are in a relationship. They’ve got someone to live for.”* [54, p. 80]. Additionally, involvement in couple relationships was described as a status symbol and expression of normality [31, 48]: *“It seems to be a way of feeling recognition somehow... to show who you are and... how many girls and boys you have met... how much sex you have. Again, it’s this thing about being “normal”*” [48, p. 537], as well as an opportunity for individuals to develop and learn from others: *“Couple*

relationships is an opportunity for personal, social, and communication development” [31, p. 6].

Subtheme 2: A problem and a source of risk

All studies reported that the sexual needs of individuals with ID were often also viewed as a source of risk [27, 29, 31, 32, 48-50, 52-57], mostly due to service users’ vulnerability and the possibility of abuse and exploitation within their relationships. As the following extract suggests, staff attitudes were generally largely conflicted and echoed a commonly reported ethical dilemma between protection and sexual autonomy, and the implications this could have for the potential violation of service users’ rights: *“He has the right to a sexual life (...) Why not? But at the same time, there’s this whole aspect of making sure that no one is at risk. Yes, he has sexual needs, so of course I’m concerned about it. But how far does it go? What rights do we have to stop this service user from experiencing sexuality?”* [32, p. 122].

Sexual behaviour was also often described as inappropriate and problematic [32, 50, 52, 54, 57] or ‘childlike’ [29]. In some studies, staff expressed ambivalent or negative views towards the issue of parenthood for individuals with ID [32, 54, 57]: *“I don’t think it’s fair to have somebody who is disabled themselves and can’t take care of themselves... I don’t mind sex but the pregnancy is not fair to the child...”* [57, p. 357]. Similarly, other studies suggested that homosexuality in individuals with ID was not viewed as a conscious choice or a legitimate expression of sexuality [51, 52] and was met with higher levels of anxiety compared to heterosexual relationships [56]. Notably, some studies highlighted that, although their participants had generally expressed supportive views about the sexuality and relationships of individuals with ID, these were not necessarily representative of staff attitudes in their organisations overall [51-54]: *“Well, a lot of the group homes there’s no real barriers there except for staff attitudes, but they’re more of an attitudinal barrier that they actually stop the training from happening”* [53, p. 143].

5.4.2. Responding to sexuality and relationships: A conflicted discourse

When reflecting on their own role in supporting the sexual and romantic lives of the individuals with ID they worked with, staff narratives often echoed an ambivalent stance. This fluctuated between the recognition of their ongoing role in supporting service users with such matters as well as a tendency to avoid dealing with sexuality directly or only deal with issues surrounding sexuality and relationships in a reactive as opposed to a proactive manner.

Subtheme 1: Supporting sexuality and relationships

Staff in ten studies expressed a desire to support individuals with ID with issues related to sexuality and relationships [27, 29, 31, 49, 51-55, 57]. For example, they commonly described that individuals with ID held poor sexual socio-sexual knowledge and recognised their potential role in helping them develop such knowledge and skills through sexual education [31, 49, 52, 54, 57]. The following extract suggests that in some cases staff felt a sense of responsibility to approach the topic of sexuality and relationships even if they were not necessarily expected to: *"But I feel obliged to widen it [the curriculum]. I don't feel I could teach fairly to students for a year and not bring in themes like sexuality. You know you spend hours talking about the rights to money and the rights to Giro, the rights to a safe working environment, when actually very few of our students really have an awareness of their money, or are going to go into paid work. But 90% of my students will at some point have a relationship"* [52, p. 120].

Staff across seven studies shared experiences of supporting service users with issues relating to sexuality and relationships in several informal ways in their day-to-day interactions with them. This most often involved helping them build socio-sexual knowledge and skills [27, 31, 49, 52, 55, 57], providing direct advice regarding relationships and sexual expression [29, 31, 52, 55, 57], supporting them with sexual health and reproduction [27] and enabling them to widen their social circle and meet

potential partners [52]. Unsurprisingly, in the majority of studies staff described their role as aiming both at promoting sexuality and protecting individuals with ID in order to make sure they expressed their sexual and romantic needs safely [27, 29, 31, 32, 49, 51, 53, 54, 57]. *“I would...say you know ‘it sounds like this is something you're interested in (watching pornography), it's something you'd like to be doing. It is an adult thing to be doing and looking at and you are an adult now. It's about exploring how to do that in a safe and protected way”* [29, p. 61].

Subtheme 2: Keeping sexuality and relationships at a distance

While most studies reported that staff did get involved in supporting the sexuality and relationships of service users, in eight studies staff reported that in their services there was also a tendency to avoid dealing with sexuality directly [29, 30, 31, 32, 49, 51-53]. For example, in some cases staff reportedly redirected such conversations or avoided proactively engaging with sexuality unless service users initiated it [29, 52, 53], suggesting that otherwise these needs remained overlooked: *“They've actually got to instigate it. It's not something we offer as a suggestion. It's not something we tend to discuss very much with the clients at all”* [53, p. 143].

Similarly, other studies reported that sexuality tended to be overlooked unless a response was necessary due to a problematic situation or an overt issue that could no longer be ignored [31, 32, 49, 52, 53]: *“The only times we talk about it are when it's problematic (...) If there's a problem related to sexuality, it will be addressed. If there is no problem, it will not be discussed and we will work on something else instead”* [32, p. 120]. Such findings suggest that there is likely a high degree of ambivalence in relation to the way staff respond to such needs.

5.4.3. Uncertainty and lack of systemic support

A consistent finding across the majority of included studies was the lack of clear guidelines regarding staff roles and responsibilities in relation to supporting sexuality and

relationships in particular, as well as a lack of training opportunities and access to information and support. The lack of guidelines and training often created a great deal of uncertainty amongst staff regarding their role in supporting sexuality and relationships.

Subtheme 1: Lack of guidelines and policy

Ten out of fifteen studies reported that the services and organisations where participants worked lacked clear policy guidelines specifically in relation to managing the romantic and sexual needs of the individuals they supported [27, 29, 30, 32, 49, 51-53, 55]. *“(Sexuality) is not really defined. (...) This is really my personal opinion, because it’s not even in our job description. There are a lot of gray areas, other things that we do that aren’t there. Maybe someday it will be included. (...) We might have to think about it as part of our basic needs”* [32, p. 120]. In some cases, where staff believed that policies might have been available, they remained unfamiliar with these [30, 50, 52] or did not mention them as overly relevant to their everyday practice [51].

In some cases, staff were only familiar with content relevant to what they should avoid doing when dealing with sexuality or with content focused on protecting individuals from potentially abusive situations [53]: *“Ah, we don’t really have any (policies) that I’m aware of, other than the client/staff policy about we’re not allowed to have a sexual relationship with the clients”* [53, p. 141]. Staff in three studies reflected on the value of policies within services and organisations and stated that further policy development was necessary in order for them to have a clear understanding of how to fulfill their roles [27, 49, 52].

Subtheme 2: Lack of training and support

In eight studies, staff described the training they had received on issues surrounding the sexual and romantic expression of the individuals they supported as extremely limited or absent [27, 30, 49, 50, 52, 54]. *“Since I started working with disability in 2008, I’ve received no sexual health training and I’m now the supervisor.”* [53, p. 142]. This, in turn, limited their confidence in their ability to respond to such needs appropriately [27, 49, 50,

52, 53]. Two studies also highlighted that the limited training opportunities available had focused exclusively on the prevention of abuse [30, 49], as opposed to promoting positive socio-sexual skills: *"We participate in watching a video which is-needs to be changes-about abuse and prevention of sexual abuse. But in terms of their rights to be sexually active, we really don't have a lot of about that, they (the agency) kind of stay away from that subject"* [30, p. 11].

Abbot & Howarth [52] also found that the link between training and policies that could back up staff decisions was missing, which led to staff feeling motivated yet powerless about introducing changes to the way they dealt with sexuality and relationships: *"People would come on the training, raise awareness, all sorts of things would be disclosed and then they would say, 'But where's the back up for us in the workplace? You know, can we allow this? Should we stop that? What can we do about whatever?'"* [52, p. 122]. Some studies also reported that lack of knowledge often led staff to seek external support or guidance from their seniors, which however was not always available or sufficient [27, 49].

Subtheme 3: Uncertainty about role

Nine studies found that, partly due to the reported lack of guidelines and training, staff experienced a great deal of uncertainty about their role in dealing with the issues of sexuality and relationships [27, 29, 30, 32, 49, 51, 53-55]. Seven studies highlighted that staff members' uncertainty regarding their responsibilities meant that they were often left to respond to situations relating to sexuality and relationships intuitively and as they deemed appropriate [29, 30, 32, 49, 51, 53, 54]. In some cases, this allowed room for staff members' own values and moral judgments to influence decisions and led to inconsistent responses to incidents where input was required [29]: *"That one would be a hard decision for me because I myself am not, I find pornography bad"* [29, p. 61].

One study [32] highlighted that uncertainty became even greater in situations with a potential to be sexually unsafe or involving an element of risk, likely reflecting staff

members' ongoing struggle between meeting service users' needs and protecting them, as well as protecting themselves. In some cases staff resolved this tension either by employing overly protective practices [32] or avoiding dealing with sexuality directly [29, 49, 51, 53]. As the following extract suggests, role uncertainty in some cases resulted in service users' rights to romantic and sexual expression being compromised as protection became a priority: *"...in a sense we did palm it off, but there's nothing in our policies as, it comes back to policies and procedures, to say what we can and can't do or whether we cross the line."* [53, p. 141].

5.4.4. Influences on decision-making

Several factors influencing decision-making in relation to issues concerning the sexual and romantic expression of individuals with ID were reported across studies. Such factors originated from employing organisations, as well as from staff themselves, service users and their families. It should be noted that, with a few exceptions, these influencing factors were most commonly described as barriers as opposed to factors that facilitated staff decision-making.

Subtheme 1: Organisational factors

Eight studies reported that staff perceived organisational factors to play an important role in determining the degree to which service users' romantic and sexual needs could be met [30, 32, 49, 52-55, 57]. Four studies reported that the ethos and, when available, existing policies of organisations were intolerant to the sexuality of individuals with ID and openly discouraged them from facilitating sexual expression [30, 49, 53, 54]. *"The message is that we (as an organization) prefer that individuals are asexual and consequently try to redirect as much as possible"* [30, p. 14]. Notably, only two studies [52, 54] provided evidence that policies in some services were viewed as helpful, for example by allowing service users access to private spaces where they could pursue intimate relationships [54]. The availability of clear rules also provided staff with certainty and legitimacy in the

face of criticism for decisions made in relation to sexuality, thus reducing their fear about the potential consequences [52]. *“They’ve got their own opinion but these are our policies and we can’t change them. We showed them the policy and said, ‘This is how we’re going to work it... they’re both consenting and we can’t stop it.’”* [52, p. 121].

Six studies referred to the living environments of individuals with ID and the set up of services as major barriers to service users’ ability to express themselves sexually and maintain relationships [32, 49, 53-55, 57]. These included practical barriers, such as the lack of private spaces [32, 49, 53, 55], as well as restrictive regulations such as a requirement for room doors to be open [54, 55]. *“Regarding roommates-time and place to set up for them to do it (e.g., masturbation)... it’s difficult in this environment because they’re not really allowed to-I feel they should be allowed (to masturbate)... to have a room to go fool around in- (but there is) no privacy-privacy is an issue”* [57, p. 356] One study highlighted that organisational restrictions could lead individuals with ID to maintain a “double life” by expressing themselves sexually in secrecy, potentially compromising their safety and integrity [55]. *“Recently I went to (facility) to do bandages for a girl who had made love in the park and her knees were completely frozen (...) (she had) third degree burns because it was winter and she had been on her knees.”* [55, p. 605].

Subtheme 2: Fear of accountability and repercussions

Seven studies reported that staff commonly experienced a great deal of fear in relation to taking responsibility for decisions made in the context of relationships and sexuality due to the potential personal and professional repercussions of such decisions [29, 30, 32, 49, 51-53]. This fear was most commonly described in the context of organisations with either unclear or restrictive policies regarding the management of relationships and sexuality. For example, staff who experienced uncertainty about policies and their own role, frequently reported a great deal of fear in relation to accidentally “crossing the line” and the negative career consequences this might incur [29, 30, 51, 52]. In some cases, staff resolved this tension by deferring responsibility to more knowledgeable colleagues or

seniors [29, 51, 52]: *"It would be quite hard if he says, 'I want this'. Sounds horrible but I don't think I'd want to, you know. I'd just get the manager involved and if something did go completely wrong it's on his shoulders isn't it?"* [52, p. 120].

Similarly, staff employed by organisations with restrictive policies described these as limiting their ability to support the sexuality and relationships of service users. Such restrictive policies were often incongruent with staff values and attitudes and as such triggered feelings of discomfort or powerlessness regarding their role, as well as an acknowledgment that acting in a way that was consistent with their personal values would lead to career consequences [30, 49]: *"I'm sitting here and I feel like a complete hypocrite, because there is so much that I would love to be able to do but my hands are tied. If they (the clients) came to me and asked me for help I couldn't do it because my job and my neck would be on the line"* [49, p. 35].

Subtheme 3: Service user factors

The role of service user characteristics was another factor reported by ten studies as influencing decision-making around relationships and sexuality [27, 29, 31, 45, 48, 49, 53, 54, 56, 57]. For example, staff described service users' level of intellectual functioning as influencing their ability to process educational materials and as such meaningfully participate in conversations about sex and reproduction [27, 31, 53], navigate relationships on the Internet [48] and consent to relationships [57]: *"I guess with people with high support needs, it's also unclear, I mean how would you go about providing some kind of sexual health education to someone who has no skills whatsoever and their cognitive ability is really, really low"* [53, p. 144]. In addition, staff were more likely to prioritise protection over autonomy for those perceived as being of lower ability [49], perceive people with profound ID as less likely to have sexual needs [29] as well as less able to control themselves and understand social norms relating to sexuality [54].

Certain individual characteristics such as level of pre-existing sexual knowledge and ability to control oneself sexually [54] were also perceived as factors facilitating staff involvement with issues surrounding sexuality. Gender was only mentioned by two studies [54, 56] as a factor influencing how staff managed the issues of sexuality and relationships. These suggested that men were viewed as more driven by sexual motives when entering relationships [56] and less able to control their sexual impulses than women [54, 56], which led to women being perceived as more innocent, sexually naïve and vulnerable [56].

Subtheme 4: The role of family caregivers

Family caregivers were identified by nine studies as playing a key role in staff's ability to support issues around sexuality and relationships [27, 29, 31, 32, 49, 51-54]. In the majority of studies, this involvement was perceived as a barrier due to family caregivers directing if and how the issue of sexuality should be managed [30, 51, 52] and as having the potential to limit or prohibit their adult children's sexual expression and autonomy [27, 31, 49, 51-54]: *"We basically can't meet the sexual health needs of the client, because the parents are giving us directives as to, this is how it's going to be"* [53, p. 143]. In some cases of family caregivers who opposed to decisions aimed at facilitating sexual expression, staff feared that negative reactions could lead to formal complaints, which further complicated their ability to fulfill their role [51].

At the same time, there was an acknowledgement that, when family caregivers acted as facilitators and supported their children's desire to be involved in relationships, this involvement was invaluable due to the amount of influence they had on other parents [54]: *"We've got such a group of parents- leaders, very open, moving forward, aware of their children's needs- not just eating and drinking but also sexual ones. And they attended this training session (on sexuality if people with ID) and they encouraged others to join it as well"* [54, p. 82]. Of note is, however, that findings regarding the positive contributions of

family caregivers in this area were only reported by one study, suggesting that the role of family caregivers was largely viewed as a barrier as opposed to a facilitator.

6. Discussion

The present review suggests that staff perceptions and attitudes towards the sexuality and relationships of individuals with ID are ambivalent, a finding that perhaps explains the inconclusive findings of attitudinal research in this area [12-18] and is consistent with those of previous qualitative reviews [11, 25, 26]. Although staff across several studies embraced the normalisation discourse and articulated a desire and moral commitment to supporting service users with sexual needs, they also voiced cautious attitudes towards their sexuality. Sexual expression was also described as a source of risk and a challenge, suggesting that it continues to be viewed in the context of risk and vulnerability [64]. Of note is that, although attitudes were arguably not openly negative or discriminatory, participants in some of the included studies acknowledged that negative attitudes were still common amongst staff in their organisations [51-54]. It is therefore possible to assume that a degree of social desirability may prevent staff from expressing openly negative views within studies or more likely, that staff holding openly negative or discriminatory attitudes may be more likely to be under-represented in research due their exclusion by self-selection bias [65].

The findings of this synthesis indicate that staff tended to respond to issues relating to sexuality and relationships in an equally conflicted manner. An exploration of the interplay between factors underlying this conflicted stance revealed that staff were required to perform their roles in a complex ethical landscape characterised by multiple power struggles and pressures. Similarly to the findings of previous reviews [11, 26], the ethical complexity most frequently cited by participants across studies was related to the issue of vulnerability and protection, which appeared to trigger both personal and systemic anxiety. In this synthesis, family caregivers were also identified by staff as a source of pressure, with such findings likely reflecting the commonly reported fearful attitudes parents hold

towards their children's sexuality [10, 66, 67], which reportedly tend to be more conservative than those of staff [10, 12]. Service ethos and restrictive policies within organisations were also found to complicate staff's ability to respond to service users' sexual needs. Compared to previous reviews of research with staff, this synthesis highlighted a greater number of organisational barriers and restrictions to sexual expression, such as limited privacy and strict regulations. Such findings are consistent with those of studies that have involved individuals with ID, which show that the set up of services and existing regulations, pressures and rules often make intimate relationships an impossible task [5, 64].

Staff's struggle to juggle external pressures appeared to be further exacerbated by a lack of training. This finding is widely consistent with existing research showing that, despite the documented effectiveness of training programmes in shifting attitudes towards sexuality [68], there is a clearly identified deficit in sexuality training within services [10, 69]. Lack of training, combined with an absence of clear policies [10], created a sense of uncertainty amongst staff regarding their roles. This subsequently led to a great deal of fear regarding the potential repercussions of taking responsibility for service users' sexuality and relationships, which has also been reported by a previous review [11]. Fear and uncertainty could in some cases further reinforce a passive attitude towards sexuality or lead to the delivery of inconsistent messages for individuals with ID. Such findings would be consistent with a large body of research with individuals with ID, who report that staff often respond to issues of sexuality selectively and inconsistently [5] and have described rules within services as unclear [70, 71].

6.1. Implications for Individuals with ID

Staff attitudes and practices towards the sexuality and relationships of the individuals they support can have significant implications on how they perceive themselves as sexual beings. By avoiding or actively discouraging sexual expression, staff may ultimately convey the message that sexuality is not an option for service users or reinforce the idea

that it is dangerous and forbidden [64, 72]. This can create a self-fulfilling prophecy where individuals with ID internalise this view and either refrain from expressing their sexuality or engage with sexuality in secrecy [5, 71, 72], thus putting themselves at potentially greater risk. Additionally, a perception of service users who are less cognitively able or lack sexual knowledge as less likely to be supported to express their sexuality [29, 48, 49], can potentially create a self-perpetuating cycle whereby service users who need it the most are the least likely to receive education and support to fulfill their romantic and sexual needs.

The findings of the present synthesis suggest that negative or even discriminatory messages in relation to certain aspects of the sexuality of individuals with ID are still likely to be communicated. This is more likely to be the case in relation to the issues of pregnancy and parenthood [32, 54, 57], as well as homosexuality [51, 52, 56]. Research in the area of attitudes towards homosexuality, which has received rather limited attention by previous reviews, suggests that homophobic responses from staff can be subtle, yet present [52]. In line with this, a recently published study amongst LGBT+ disabled youth [73] found that the sexual orientation of individuals with ID was often delegitimized, by being described as a 'phase' or a result of their disability, and individuals with ID themselves were often viewed as incapable of making informed choices about their sexuality due to their disability. Taken together, such findings suggest that certain groups of individuals with ID may be more likely to experience discrimination within their environments, with this having the potential to cause isolation and lead to confusion and shame about their sexual identity.

6.2. Implications for Staff and Services

The findings of this review further emphasise the requirement for service policy development specifically in relation to sexuality and relationships, which based on the present findings, is most often either absent or restrictive. The availability of clear policies within services can ensure that service users' rights are not violated, but also provide staff

with a guideline which can alleviate concerns regarding accountability and repercussions from employing organisations or family caregivers. As policy development is inextricably connected to funding and identified service priorities [53], it is likely that for such changes to occur at a service level, there needs to be a shift in national policy priorities. In that direction, the Care Quality Commission in the UK has recently published a guidance for “Relationships and Sexuality in Adult Social Care Services” [74], which outlines the responsibilities of service providers in meeting those areas of need for service users. Although this is a promising step, ongoing monitoring of the implementation of such guidelines may be required and policy with a more specific focus on ID and sexuality might need to be developed. Hopefully, such developments can gradually lead to a change in culture within services and the elimination of disempowering and restrictive views.

In agreement with previous authors [11, 25, 26], the present review concludes that sufficient and timely training on sexuality is necessary. However, it is worthwhile considering whether traditional training may not be sufficient. For example, based on the findings of the present synthesis, training is more likely to be effective if it maintains close links with policy regarding the implementation of knowledge in practice and within specific staff roles, otherwise, it can lead to a sense of powerlessness [51]. Additionally, with sexuality in the population of individuals with ID being an ethically complex and provocative subject, training may need to be supplemented with opportunities for staff to engage in reflective practice and more meaningful supervision and modelling by senior members of staff. This could alleviate anxieties, help staff manage external pressures and allow them to reflect on how their own values and attitudes may interfere with their practice. Lastly, given the extremely influential role of family caregivers in decision-making surrounding sexuality, it is likely that training tailored to their needs is a prerequisite for any meaningful change in the way such matters are managed within services.

6.3. Strengths and Limitations

Given the growing interest of qualitative research on the experiences of staff in relation to supporting the sexuality of individuals with ID, this review is valuable as it provides an up to date overview and quality appraisal of available research. Unlike previous recent reviews conducted in this subject area [25, 26], the qualitative synthesis of previous findings in this review enabled the aggregation of participant perspectives from multiple studies and allowed for an in depth exploration and demonstration of staff attitudes and practices, as well as of the interplay between factors influencing these. By highlighting such processes and factors influencing decision-making and staff practices, the present review was able to combine existing knowledge and use it to make recommendations for practice.

A possible limitation of the present review is related to the well-documented [36] difficulties inherent in searching for qualitative literature in electronic databases. Of note is that a quarter of the articles included in this review were identified through a manual search. Although all measures were taken to avoid the accidental omission of relevant studies, for example by contacting other researchers in this area, there is still potential for human error. Furthermore, in this review a decision was made to exclude grey literature. Although such a decision has the benefit of ensuring the quality of articles through the process of peer review, it is possible that the inclusion of unpublished research, such as dissertations and theses, might have enriched the findings and would have reduced publication bias [75].

Although the present review aimed to include studies using samples of a wide range of staff, there was an over-representation of support workers in the overall sample of included studies and therefore this may have impacted on the nature of themes that emerged as important. For example, as direct care staff are less likely to have received sexuality training compared to staff employed in managerial or clinical roles [69], it is possible that themes related to role uncertainty and powerlessness are more relevant to

that professional group compared to others. Nevertheless, attention was paid during the analysis to ensure that produced themes were, as much as possible, representative of the dataset overall in order to mitigate the risk of providing a biased picture of staff experiences.

6.4. Research Recommendations

Future primary research, as well as reviews may find useful to more specifically consider exploring the experiences and views of other professional groups that remain largely under-represented in research, such as nurses, doctors, social workers and psychologists. Of note is that only one study included in this review reported the views of managers separately from other professionals [36]. Given the crucial role of service managers in the implementation of training and policy as well as in overseeing staff working practices, exploring their views can valuably add to our understanding of how service cultures can shift and adapt to meet the romantic and sexual needs of service users. Additionally, given the evidence provided by this synthesis in relation to the prevalence of negative or discriminatory attitudes towards certain aspects of the sexuality of individuals with ID, such as homosexuality and parenthood, future research exploring these attitudes specifically could provide valuable information regarding underlying factors influencing these and identify mechanisms of change. Lastly, it might be helpful for future evaluations of sexuality training programmes for staff to consider the potential contribution of additional elements, such as reflective practice and supervision, to outcomes related to attitudes and practices.

7. Conclusion

In conclusion, the present review provided an overview, quality appraisal and synthesis of previous qualitative research in the area of staff perceptions and experiences in relation to supporting the sexuality and relationships of individuals with ID. Despite its identified limitations, this review added to existing knowledge produced by previous reviews by

including more recent literature published in 2019, and conducting a qualitative synthesis of previous findings. Findings from the synthesis were discussed in the context of previous research and were utilised to make recommendations for staff and services, with the ultimate aim of ensuring that individuals with ID continue to be supported to build knowledge and skills and are empowered to fulfill their rights to sexual and romantic expression in a meaningful manner.

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Journal Article 2: Empirical Paper

Mothers of adults with Intellectual Disabilities: Experiences, perceptions and influences on their sons' and daughters' romantic and sexual lives.

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Written in accordance with submission guidelines for Sexuality and Disability (See
Appendix 1 for Author guidelines)

1. Abstract

Background: Despite a growing research interest in the romantic relationships and sexuality of individuals with Intellectual Disabilities (ID), little attention has been paid to the way family caregivers understand and manage these issues. This study aimed to explore the views and experiences of nine mothers of adult individuals with mild/moderate ID in relation to their children's romantic and sexual lives. *Method:* Data was collected using a semi-structured interview and was analysed using Interpretative Phenomenological Analysis (IPA). *Results:* Most mothers reported that their sons and daughters were interested in relationships and curious about sex, and described their previous and current relationships as similar to 'typical' relationships, yet different in certain aspects. Mothers described their sons' and daughters' sexual knowledge as poor and reported lack of proactive and preventative sexual or contraceptive education. Mothers reflected on their role as involving both facilitating relationships and protecting from risk, and described available supports in relation to sexuality and relationships as being valuable. They expressed hope that their children would be able to form romantic relationships, but these were widely viewed as unlikely to be sexual. *Discussion:* Findings suggested that mothers expressed positive views about relationships and held the dual role of a facilitator and a protector in their children's relationships. Mothers however made a distinction between romantic and sexual relationships, expressing caution and ambivalence towards the latter. Findings suggest that more emphasis should be placed on helping mothers to proactively support their adult children in building sexual knowledge. Suggestions for future research are discussed.

Keywords: Sexual, romantic, Intellectual Disabilities, experiences, mothers, qualitative.

Word Count: 12,039

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2. Introduction

Involvement in romantic and intimate relationships is a major developmental task of adulthood [1], with a range of psychosocial benefits for individuals [2]. The romantic and sexual expression of individuals with Intellectual Disabilities (ID), however, has historically been a neglected area and has often been governed by stereotypical perceptions of this group as either non-sexual beings or as hypersexual [3]. The philosophy of normalisation, which was introduced in the 1970s to promote equal rights, created a gradual shift in public perceptions of individuals with ID leading to their recognition by the Human Rights Act [4]. In the UK, these rights have received attention by national policies [5] and voluntary organisation campaigns, which aim to promote the rights of individuals with ID, including their right to engage in romantic relationships [6].

A growing body of research amongst individuals with ID suggests that intimacy is valued and the desire to be in relationships is present [7, 8], however the social opportunities or socio-sexual knowledge to do so safely are often lacked [7, 9]. As individuals with ID have fewer opportunities than their typically developing peers to obtain sexual knowledge through peer interaction [10], parental influences can be crucial in determining their attitudes and access to socio-sexual information. In addition, given the continuous involvement of parents in their children's life during adulthood [11], parental influences may also determine the level of social and sexual autonomy individuals are able to achieve [12]. Although parental support and guidance can facilitate engagement in relationships, individuals with ID commonly report feeling overprotected by their caregivers [7, 13].

Although family caregivers generally express positive attitudes about their children's rights to romantic and sexual expression, they frequently report cautious attitudes towards sex education, show a preference for their child having low levels of intimacy and discuss only few topics mainly focused on safety [14, 15]. Studies have found older parents to hold

more conservative views compared to younger parents [14, 16, 17] and family caregivers to hold more conservative views compared to staff [14, 16]. Such findings, however, may be confounded by age, as family caregivers tend to be older than staff members [16]. A limitation of this line of quantitative research is that self-reported attitudes do not necessarily translate into practice [17] and as such, they provide limited information about parental behaviours and underlying factors influencing these. In this context, qualitative research can be useful as it can shed light on relevant influences and underlying processes [18].

To date, only a limited body of qualitative research has explored the views and experiences of family caregivers in relation to the romantic and sexual lives of their adult children. Rushbrooke and her colleagues [19] conducted a qualitative meta-synthesis focusing on the challenges faced by formal (i.e. paid) and informal (i.e. family) caregivers in relation to the sexuality of adults with ID. Although this review had a somewhat disproportionate focus on formal as opposed to family caregivers and included studies that lacked a specific focus on sexuality or relationships [20, 21], it provided some valuable conclusions. More specifically, it suggested that family caregivers expressed fear and uncertainty, as well as lack of confidence raising the issue of sexuality. They expressed positive attitudes towards their adult children's sexual expression, however described sexuality as conditional and acceptable within certain limits. Caregivers also expressed their struggle to provide support to individuals with ID with relationships whilst protecting them and managing risk, and identified a need for more training and support from services.

More recent studies have explored the experiences of mothers in relation to supporting the sexual development of their adolescent and young adult sons and daughters with ID [22-24]. This research highlighted the tensions experienced by caregivers between their roles as facilitators and protectors of individuals with ID and overall suggested that parents perceived their sons' and daughters' sexuality as challenging and anxiety

provoking [22-24]. Findings also highlighted that parents felt ambivalent in relation to providing sex education [22], tended to avoid or prevent the sexual expression of their sons and daughters [24] and prioritised the protection of individuals with ID, as well as the protection of family and religious values, over the promotion of sexual autonomy [23].

Although existing qualitative research with family caregivers has provided some valuable insights, two limitations can be identified. Firstly, almost all studies have had a primary focus on parental views in relation to the sexual aspects of their children's relationships, perhaps overlooking emotional and social aspects of these, as well as the emotional meaning attached to them by individuals with ID and their families. Secondly, most research to date [20, 22-27] has focused on parental perceptions of the emerging sexuality of adolescents and young adults, as opposed to the perceptions of individuals' experiences as they progress through adulthood. It is possible to assume that parents of older individuals may face different challenges. For example, there is preliminary evidence suggesting that older individuals may be more likely to experience perceived inequality as a result of witnessing their siblings getting involved in relationships or getting married as they grow older [28].

An exception to the limitations mentioned above is a recent study [29], which was published while the present research was underway. Neuman [29] explored parental perceptions on the couple relationships of adult individuals with ID living in Israel, with a focus on their wider romantic experiences as opposed to just sexuality, and used a sample of parents of individuals of a wider age range (22-53 years old). His findings suggested that parents were supportive and encouraging of their children's couple relationships, however were more likely to view them primarily as a source of physical intimacy as opposed to meeting emotional or social needs. Parents described that their sons and daughters had frequent difficulties within these relationships due to cognitive and social limitations, and often relied significantly on external help such as direct support staff. Although parents expressed positive views about physical intimacy within couple

relationships and encouraged it, there was an expectation that this would occur when their children were 'ready'. Still, such findings provide a much more positive picture of parental attitudes compared to previous studies. This should perhaps be interpreted with caution, however, as the authors acknowledged that the strong emphasis on the importance of family and couple relationships in the Israeli culture may have contributed to these findings. In addition, this study included only parents of individuals who lived in group settings outside the family home. It is therefore possible that a range of issues related to the management of relationships and sexuality commonly perceived by family caregivers as challenging, were managed by support staff as opposed to parents themselves.

3. Rationale for the Present Study

In summary, qualitative research to date has provided some valuable insights into parental experiences. It has, however, been rather limited and largely concerned with the perceptions of families of adolescents and young adults with ID in relation to sexuality, as opposed to the perceptions of families of older individuals with ID in relation to their wider romantic and sexual experiences. This study aimed to address these gaps in research, further add to the understanding of parental experiences and ultimately highlight areas of need and further support. To achieve this, it employed a qualitative design to explore mothers' experiences, perceptions and influences on their adult sons' and daughters' romantic and sexual lives. The focus on mothers was decided on the basis of research suggesting that mothers tend to be the primary care figures in the lives of individuals with ID [14] and, compared to fathers, are more likely to engage in discussions around relationships and sex [14, 30]. Evidence therefore suggests that their views and experiences might differ and as such may be worthy of exploring separately. This study aimed to recruit mothers of adults without setting an upper age limit, in order to allow for the inclusion of mothers of older individuals and facilitate the exploration of potential differences in parental experiences depending on their sons' and daughters' age.

4. Method

4.1. Participants

Participants were recruited from voluntary social groups run by families of individuals with ID and through snowballing techniques. They were mothers who met the following criteria; they had a son or daughter older than 18 years old with a mild or moderate ID, they were fluent in English and they had capacity to provide informed consent. No formal evidence of a diagnosis of ID was required, however participants' sons and daughters had a reported history of previous assessment for ID and involvement with ID services. The severity of participants' sons' and daughters' ID was established on the basis of mothers' self-reports. Although this study used a convenience sample, services with a specific focus on providing support to individuals with ID and their families in relation to dating, sex and relationships were not approached. This was based on the assumption that the experiences and attitudes of families already accessing such services might not be typical of the population overall.

Participants for the study were nine mothers of individuals with ID ranging from mild to moderate in severity. In order to facilitate the interpretation of the data, information regarding participants' children's characteristics (e.g. gender, age, severity of ID, level of support required, residential placement, relationship status) was collected using a questionnaire developed by the principal researcher (Appendix 6). Mothers' age ranged from 44 to 70 with an average age of 53. Participants' sons (n=4) and daughters (n=5) were between 18 and 41 years old, with an average age of 25 years old. A summary of additional information regarding participants' adult children collected through the questionnaire can be found in Table 1. Although additional information regarding any comorbid diagnoses was not collected through the questionnaire, this was informally explored with participants during the interviews. Three participants reported that their children had a comorbid diagnosis of Autism Spectrum Disorder (ASD).

Table 1. Additional Information Regarding Participants' Adult Children

Characteristics	Description	N=9
Gender	Male	4
	Female	5
Age	18-25	5
	25-35	3
	35-45	1
Severity of ID	Mild ID	4
	Moderate ID	5
Level of support required	Requires some support, but not on day to day basis	1
	Requires a lot of support on a day to day basis	8
Residential placement	Living at family home	9
Current relationship status	Single	8
	In a relationship	1
Historical relationship status	Believed to have previously been in a romantic/ sexual relationship	5
	Not believed to have previously been in a romantic/sexual relationship	4

4.2. Data Collection and Procedure

Individual interviews were conducted with participants in community settings that provided privacy and lasted between 23 and 44 minutes. A semi-structured interview was used for data collection (Appendix 7). This was developed following a review of the existing literature, discussion with the research team as well as discussion with a group of mothers of individuals with ID. It included open-ended questions aiming to obtain detailed and rich narratives. Examples of questions included *“What would you say are your hopes/fears in terms of your son/ daughter’s romantic life?”* and *“What kind of support have you or your son/daughter had in terms of romantic or sexual relationships?”*. Prior to the interviews, the researcher explained the aims of the study to participants, sought their informed consent and made sure that they were put at ease. Interviews were digitally recorded and transcribed verbatim by the main researcher using electronic software. During

transcription all identifiable information was removed and names were replaced with pseudonyms. The first two conducted interviews were treated as a pilot of the interview schedule. As no amendments to the original interview schedule were considered necessary, this data was included in the main study.

4.3. Researcher Reflexivity

Throughout the research process, the researcher reflected on the influences of her own beliefs, expectations and experiences on the interpretation of the data through the use of a reflective diary. The researcher remained aware of her experiences of having worked with individuals with ID in a clinical capacity and the potential ways in which this might influence her interpretations of participants' accounts. The researcher was also aware that, due to the predominantly negative discourse around sexuality and ID in the research literature, during data analysis she experienced a desire to provide a more positive picture by emphasising strengths and positive meaning in participants' accounts. The researcher remained mindful of the impact this might have on the representativeness of the produced themes and managed it by continually re-engaging with the data and comparing her analysis against participants' accounts and process of meaning-making.

4.4. Data Analysis

Transcribed data was analysed using Interpretative Phenomenological Analysis (IPA). IPA is a qualitative method, which is underpinned by phenomenology and hermeneutics, and is concerned with the detailed exploration of participants' personal perspective and attempts to make sense of their world [31]. IPA acknowledges and values the contribution of the researcher's own perceptions and interpretations to the analysis of participants' accounts, a process that has been described as a "two-stage interpretation" or "double hermeneutic" [32]. Following the steps suggested by Smith and his colleagues [33], each transcript was initially treated as an individual case study. After reading the transcripts several times, exploratory descriptive, linguistic and interpretative comments were made

and clusters of emergent themes were drawn together. During this process the researcher continued to check her own interpretations against the participants' accounts. The above steps were repeated for each transcript, subsequently allowing for superordinate and subordinate themes that reflected the dataset as a whole to be identified.

Several steps were taken to promote the rigour of data analysis. In order to achieve coherence, the researcher developed competence and knowledge regarding the philosophical and theoretical background of IPA, and ensured compliance with the method through reflection and use of supervision. A second researcher reviewed samples of transcripts and emerging themes and, at the stage of data analysis, the principal researcher sought participants' feedback on the emerging themes. From the total of seven participants who provided their consent to be contacted at the stage of analysis, only one provided feedback, and this was incorporated into the analysis. The principal researcher also kept a reflective journal throughout the research process to guide and facilitate the analysis.

4.5. Ethical Considerations

The study was granted ethical approval by the University of Edinburgh Ethics Committee in March 2019 (Appendices 8 and 9). The potentially emotive nature of the topics covered in the interview and the protection of participants' confidentiality were amongst the ethical issues considered. Relevant permissions from voluntary organisations involved in recruitment were also sought where required.

5. Results

As illustrated in Table 2, five superordinate themes emerged from the data analysis, comprising fifteen subordinate themes. Each subordinate theme was evidenced by data collected by at least three participants, in line with the recommendations made by Smith and colleagues [33]. During the presentation of the results, the term "children" is often

used to refer to participants' sons and daughters. It should be noted that, as all participants' children were over the age of 18, the term is used to indicate their relationship to participants as opposed to their age.

Table 2. Summary of Superordinate and Subordinate Themes

Super-ordinate Themes	“Just like everybody else”	“But is it really the same?”	“Risk and Vulnerability”	“Facilitating and Protecting: A fine balance”	“Exploring personal meaning and hope”
Sub-ordinate Themes	“Relationships in their radar”	“Is it really romantic?”	“So vulnerable that you just constantly worry”	“Making it happen”	“The way we are meant to be: Exploring the meaning of relationships”
	“Boyfriend-Girlfriend”	“Talking about sex: It goes over her head”	“This girl-boy thing is very different”	“Measures in place”	“Hoping they can manage it one day, but probably not sexual”
	“Curiosity about sex”	“All sorts of barriers”	“She had never been rejected before”	“Getting help when necessary”	“Something that I miss for her, that she's never missed”

5.1. “Just like everybody else”

Most participants talked about their sons and daughters displaying romantic interest, expressing a desire to be involved in romantic relationships and sometimes being curious about sex. Some participants reflected on their children's previous relationships and generally described these as involving elements most commonly associated with romantic relationships. Their narratives indicated that, in some aspects, their children's romantic needs were viewed as not different to anybody else's.

5.1.1. “Relationships on their radar”

All but one participant described that their sons and daughters had been curious about or interested in relationships and had occasionally demonstrated an awareness of various

aspects of romantic relationships such as dating, kissing and marriage. Most participants described their children as having shown romantic interest from a young age, for example by having “boyfriends” and “girlfriends” in Primary school. Some participants identified a developmental change as their children grew older; this involved developing a “type” they were attracted to or expressing romantic interest more actively, for example by exchanging their first kiss or asking if they could go on dates: *“As she was getting older you know maybe fourth year or fifth year she would come home from school saying “when can I go on a date?” (Participant 5)*

Three participants, who were all mothers of older individuals with ID, reported that their children desired to get married and have children in the future, and identified having witnessed other family members getting married and having children as a significant influence on their expectations from their own romantic lives. The following extract suggests that this expectation may have also arisen through discussions that had taken place within the family, which had created an expectation that marriage was a plausible outcome: *“And I always used to say “there are lots of people in the family to get married before you”, her cousins for instance who are both married now. So she’ll see that it’s her turn next. What you want to do is the same as everybody else” (Participant 9)*

5.1.2. “Boyfriend and Girlfriend”

Six out of nine participants believed that their children had at some point in their lives had a boyfriend or a girlfriend. Without making an explicit distinction, participants talked about certain elements of those previous or existing relationships that differentiated them from friendships. In some cases, the couple had made a conscious decision to progress a relationship from a friendship to a romantic status or to publicly share this new status: *“They had known each other for a long time through a group and then all of a sudden they became boyfriend and girlfriend” (Participant 9)*

"We had family things going on and when she had a birthday party Blair was there and she introduced him to everybody "this is my boyfriend" and all the rest of it" (Participant 1)

There was also an implication that romantic relationships involved exclusivity resulting from not dating others as well as some level of maintenance, such as going on dates regularly and talking on the phone. As opposed to other social encounters, in the context of romantic relationships individuals also experienced an additional level of independence and privacy: *"They go out and have a wee date and go to the pictures and they go for dinner and then he tends to walk her home and make sure she's safe" (Participant 6)*

5.1.3. "Curiosity about sex"

None of the participants believed that their sons and daughters had been sexually active. In the majority, however, participants described that their children had, at some point in their lives, expressed curiosity about sex either by asking questions or making statements about sex: *"We were in the car one day, I looked in the mirror and she says "Mum, when can I start sleeping with Stewart?" (Participant 2). All participants stated that sexual education had been provided within school and there was a shared view that this had in some cases triggered more curiosity about sex, which many of them reacted to with surprise. This would suggest that in most cases, this was perhaps the first time the topic of sex was being talked about at home: "They did a bit at school, some sexual education and the first time he said something about a penis, I was like "what?" (with emphasis), "where did you get that from?" (Participant 7)*

Even in the absence of their sons' and daughters' explicit interest in sex, there was an acknowledgement that sexual desire was present. For example, two participants described that their son and daughter were engaging in masturbation, and this was described as a healthy release of sexual tension. Of note is that, although two more participants identified their sons as experiencing sexual arousal, they did not believe they had successfully mastered the skill of masturbation. Although some limited discussions

regarding this had taken place at home, usually initiated by the fathers, no further action had been taken to ensure masturbation was possible, indicating that it was perhaps not viewed as a topic they could comfortably discuss.

5.2. “But is it really the same?”

Despite acknowledging the presence of romantic interest and desire, participants’ accounts suggested that they frequently questioned their adult children’s romantic intent, the quality of their romantic relationships and the genuineness of their curiosity and interest in sex. This narrative, which was rather contradictory to their previous descriptions of their sons’ and daughters’ interest in relationships and relationship experiences, frequently echoed a discourse of what is “normal” or socially expected in the context of relationships.

5.2.1. “Is it really romantic?”

Several participants explicitly or implicitly questioned whether the romantic intent their children expressed necessarily translated into a genuine desire to be involved in a romantic relationship. For example, the following participant described her daughter’s intention to be involved in a romantic relationship as driven by a need for social acceptance and inclusion, indicating that the expressed desire was guided by societal expectations as opposed to a need for connection: *“She just thought that that’s what she should be doing rather than what she wanted to do (...). Probably peer, not peer pressure, but what her peers were doing as well. And obviously she sees things in television and on the Internet and she very much wants to be a normal girl” (Participant 3)*

For some participants, a similar belief was based on their view that their adult children did not display a proactive attitude with regard to pursuing a relationship or making it a priority. Interestingly, although this “passive” attitude was often described as a result of individuals’ cognitive limitations and poor social skills, it was frequently interpreted as

evidence that their interest might not be genuine: *"Sometimes she will say 'I think I'd like a boyfriend' (...) if she came to the club today and she was up dancing with a boy there's no way I would stop her but she just doesn't do that. She wants me to dance with her. She talks a good game as I said, she talks about normal, I hate that word, but normal things."* (Participant 9)

In their narratives, mothers sometimes also described these relationships as "childish" or resembling friendships. Their accounts often echoed an implicit view that these relationships lacked certain elements that would qualify them as being "romantic", such as involvement in shared activities, reciprocity and physical intimacy beyond hand holding and kissing: *"I believe it was more like a friendship. I do think they did kiss and I know they did use to hold hands because she made him"* (Participant 1)

"He is not your boyfriend, just a friend you have in school. Because he doesn't take you on dates. Until he takes you on a date, he is not your boyfriend" (Participant 5)

5.2.2. "Talking about sex: It goes over her head"

Despite acknowledging that their adult children showed curiosity or made statements about sex, almost all participants reflected that in reality they had very limited understanding of the concept of sex. Although all participants reported that their children had received sexual education at school, the general consensus was that this had only had a limited impact on their understanding, which remained relatively poor: *"You know she has come home and said so and so and so were kissing you know how in school they tried to talk about sex education (...) and she would come home and say 'oh we had that today' and I would say 'all right, what were they talking about?' and she'd be like 'I don't know'. It goes over her head"* (Participant 5). This narrative of individuals with ID as not able to process or understand sexual concepts, often led to participants interpreting their sons' and daughters' statements or questions as attempts to elicit a reaction rather than communicate a need, meaning that these were perhaps not perceived as worth following

up on: *“He did mention the word vagina once so he did know the words, but I think he knew that he was getting a reaction when he was saying them. Because we all looked at him when he said them and we knew that he must have been getting sexual education”* (Participant 7)

Of note is that, despite the identified gap in understanding of issues surrounding sex, only two participants described having had additional, detailed discussions about sex at home. There was an acknowledgment that this was due to their children not actively trying to find out more about sex or initiate such conversations. This expectation that the individuals with ID would initiate such conversations suggested that participants often felt that it was better to avoid this topic unless guidance was actively sought by their children. As illustrated in the following extract, this might also reflect a worry around creating more curiosity or creating further problems if such topics are raised before the individual with ID is considered to be ready: *“Because if she doesn't ask the question I just always think she's not thinking about it. So there's no point going there if that hasn't gone into her mind yet”* (Participant 5)

5.2.3. “All sorts of barriers”

Participants spoke about several barriers that could compromise their sons' and daughters' ability to get involved in and maintain relationships. Some reflected on their children's limited understanding of the social rules that typically govern relationships, such as monogamy and reciprocity. Interestingly, this was a concern predominantly expressed by the participants whose children had a confirmed or suspected diagnosis of ASD in addition to ID, potentially due to the social deficits often present in individuals with ASD. In some cases, participants expressed a concern that, due to these limitations, their children might accidentally hurt others, for example by going out with two people at the same time. As illustrated in the following excerpt, others expressed a concern that their children might not be able to find someone who would “tolerate” them: *“A relationship with a person is a*

two way thing and Olivia is not going to give anything, she's going to keep everything to herself (laughs). You would need to find someone who could do that and he (her previous boyfriend) had years of it and I'm not joking, he wasn't even given time to say hello on the phone" (Participant 2)

Across participants' accounts there was also a general sense that a potential partner would need to be able to handle certain aspects of their needs arising from their ID and/or ASD, such as performing personal care or being able to handle challenging behaviour in public. As illustrated in the following extract, for some participants, this narrative led to a realisation that finding a partner who would be able to fulfil the role they themselves previously occupied would be hard, and might in fact be impossible: *"But saying that, who's going to change her bum? Clean her? Do all the things? Shower her? I've tried it for so many years to teach her to wash, toilet herself and she still can't do it" (Participant 8)*

5.3. "Risk and Vulnerability"

Participants expressed great fear in relation to the possibility of their sons or daughters being taken advantage of by others emotionally, physically and sexually. They frequently discussed their children's own experiences of harassment or shared stories of abuse that had recently been shown in the news, suggesting that they remained continually vigilant to potential risks. Participants described their sons and daughters as vulnerable on multiple levels and across their accounts there was a sense that the nature and level of risk was partly dependent on the individual's gender.

5.3.1. "So vulnerable that you just constantly worry"

Participants talked about their sons and daughters as vulnerable due to their limited understanding of sex, consent and personal space. Almost all participants expressed a fear that their adult children might become victims of exploitation and abuse, and described several behaviours they engaged in, such as taking their clothes off when

others were present or being overfamiliar with strangers, which could place them at risk. Participants generally shared the view that their sons and daughters were most often oblivious to their vulnerability or risks: *“Obviously because she can’t, well at this moment in time she can’t stand up for herself, she doesn’t realise how vulnerable she is and doesn’t realise the impact that vulnerability has on her life, does that make sense?”* (Participant 5)

Some participants reflected that, due to their sons’ and daughters’ limited ability to identify risks, they often felt unsure about whether they would be able to alert their families if something was wrong: *“I suppose a worry is that she gets involved with somebody and she doesn’t feel that she’s happy with them and then maybe not know how to get out of a relationship. You know, she might just keep it all to herself and you know, let it all build up”* (Participant 3). This narrative suggested that, although most participants’ sons and daughters had received some education about risk and protection, they were generally not viewed as capable of protecting themselves and safeguarding was viewed as the responsibility of their families. Three participants reported previous incidents where their sons or daughters had been sexually harassed. These often involved other individuals with ID and in some cases, peers without ID. There was a general sense that, although such incidents had, to some extent, been unsettling for the individuals with ID themselves, due to them being of a young age or being unaware of the risks involved, it was predominantly their families that had to live with their emotional implications: *“She didn’t know how severe it was, but for me... it was for me. I was really hurt and felt invaded but Olivia, no, she didn’t care”* (Participant 2)

5.3.2. “This girl-boy thing is very different”

The predominant theme discussed in the context of gender was that of sexual relationships, possibly due to the more complicated nature of consent involved in such scenarios. Participants’ accounts often revealed stereotypical views on gendered sexual

behaviours echoing a discourse that portrayed females as potential victims and males as potential perpetrators. The following participant refers to “rape” as her greatest concern, implying that if both parts involved in the sexual relationship had limited understanding of consent, the male partner would be more likely to be held accountable: *“If (you had a girl) you would still be concerned that they would be forced upon (...) but obviously I have the boy so my concern is the other side of it. That she wasn't maybe quite understanding, basically rape. You know, that would be my fear. And that's not in his nature whatsoever but you are just not sure how other people would misread that”* (Participant 6)

Females were also described as facing greater risks by three participants, who directly expressed a belief that having a daughter with an ID created more concern due to the possibility of a pregnancy, which could then be perceived as the responsibility of her family. Despite being the mother of a son, the following participant describes the often reluctant and fearful attitude held by other mothers, whose daughters have been involved with her son, as understandable and reflects that she herself would not be as open-minded if she had a daughter with ID: *“I think this girl/boy thing is very different. I think it is. I think if I had a girl what I would be worried about is a baby. That's what my fear would be. I don't think that's the same if you have a guy because that would then not be so much our problem, that would be the girl's problem and I think that's why the mums have been the way they have with him”* (Participant 1)

5.3.3. “She had never been rejected before”

Participants talked about the emotional implications rejection and relationship breakdown had on their sons and daughters. There was an acknowledgement that involvement in romantic relationships exposed individuals to emotional risks, such as being rejected, that they had never encountered before. There was also a sense that, for their child to be involved in a romantic relationship, participants had to give up some of the control they had over their emotional lives up until that point, meaning that the individual with ID,

perhaps for the first time, had to process and cope with difficult emotions independently:

“Unfortunately one day she came home and she said that he didn't want to be her boyfriend anymore because he didn't have time and she was absolutely devastated. It was probably a form of rejection to her and she's never been rejected by anybody in her life because she's always been in a very safe environment with family and friends (...) it was a very difficult time in that you felt so helpless because you couldn't make it right, whereas in her life anything else that happened we could always make it right” (Participant 9)

Participants also indicated that their adult children often found it hard to navigate more complex or emotionally challenging aspects of relationships, such as not having their romantic interest reciprocated or realising that their partners had met someone new and wanted to end the relationship, and this was often expressed through sadness and upset:

“But the downside to that is that when it ends, he can get really down. And that side of that, “why am I not good enough, what did I do wrong” (...) you try to explain to him that they've, not everybody feels the same. It's difficult to explain to him how everybody doesn't feel the same way, that maybe they met somebody else, so it can be a bit of a mine field” (Participant 6)

5.4. “Facilitating and protecting: A fine balance”

Participants reflected on their role in supporting their sons' and daughters' romantic lives, which was often described as necessary for the maintenance of their relationships. Participants also reflected on possible limitations to their role and the need to find other support when necessary. Although their narratives generally revealed positive attitudes towards the romantic lives of their sons and daughters, there was a general sense that certain aspects of these relationships, especially when it came to their potential to become sexual, were perhaps less easy to accept or support.

5.4.1. "Making it happen"

All participants reflected on the fact that, if their son or daughter wished to pursue a romantic relationship, they and the rest of their family would most definitely support them. Several participants described arranging and setting up dates for their sons or daughters as a key element of their role, and this most often was through communication with their partner's family. Some participants expressed negative feelings about this level of involvement, for example by reflecting on having to be present during dates, which felt intrusive and uncomfortable. As illustrated in the following extract, for others this level of involvement was a difficult reminder of their sons' or daughters' limitations: *"I have to do the dates, I have to arrange the dates, I have to keep it going. I have to arrange with the mum, because Olivia is not able to arrange with that person. Every time it will be me and the other mum making the arrangements. You know what I mean, it wouldn't be Olivia, she's not able to do that. And that's the sad thing about it that she is not able to do that"* (Participant 2)

Participants frequently described their involvement in their sons' and daughters' relationships as not being limited to practically facilitating dates, but also extending to providing ongoing social and emotional coaching. This often involved encouraging them to go out and socialise or, as illustrated in the following extract, advising them on the social rules attached to meeting potential partners and dating: *"And you know what I've tried to say to her is "if you're in a club or if you are somewhere else and someone asks you if you have a boyfriend, tell them no". And if they want to be your boyfriend and you like them, then you say yes and then they ask you to go on a date"* (Participant 5)

5.4.2. "Measures in place"

The majority of participants were their children's nominated Legal Guardians, and their narratives echoed the conflict of supporting healthy relationships whilst providing protection. Most of these discussions were held in the context of the perceived sexual

risks involved in sexual interactions and relationships. Despite expressing liberal views regarding the possibility of a relationship becoming sexual, this was widely described as conditional upon certain factors, such as meeting the “right” person and being in a “secure” relationship. For most participants, there was a lack of clarity as to who would make the judgment about whether these conditions were met. As illustrated in the following extract, for Participant 3 this would be someone of a similar level of ability who her daughter felt safe and happy with: *“Yeah, we would all encourage it as long as it was the right person (...) someone who cared for her and wouldn't take advantage of her basically. And who she thought, you know, that she wanted to be with. So yeah, I wouldn't rule anything out. As long as she was happy with who it was. Obviously you wouldn't want someone who is maybe quite you know, highly intelligent. You would be, you would wonder what their motives were, you know to be with a young girl with learning disabilities” (Participant 3)*

Only one participant spoke about sex as being definitely discouraged, by ensuring that her daughter was never alone for sexual activity to take place. Other participants spoke about practical measures that might need to be put in place such as making sure that any interactions with the potential to be sexual were only taking place at the girl's home: *“If there was any canoodling it would be in my house. I'd rather have it in my house. It wouldn't be in anybody else's home, it would in mine where she would feel safe and secure” (Participant 8)*. Of note is that only one participant raised the issue of contraception as important when considering sexuality, by stating that she would seek contraceptive advice to eliminate the possibility of a pregnancy should her daughter get involved in a relationship. The absence of the issue of contraception from participants' accounts would indicate that unless individuals with ID were in a relationship with a potential to be sexual, contraception was not considered an essential preventative measure that needed to be explored.

5.4.3. "Getting help when necessary"

Participants spoke about certain limitations to their role and reported having to seek support in relation to sex and relationships. Three participants reflected on having found the input of social workers, nurses and psychologists valuable. This, however, was largely described in the context of the person with ID having encountered difficulties in their relationships rather than as a preventative measure, suggesting that the day-to-day management of issues surrounding sex and relationships came primarily from the family: *"We also had a learning disability nurse. She did a bit of work with Blair as well roundabout when this wee girl was mucking with his head, really something terrible"* (Participant 1)

The participants who had discussed experiencing feelings of discomfort in relation to the intensity of their involvement in their children's relationships reflected on the valuable input of support workers, who often took on that role by supporting their sons and daughters to go out on dates and providing information about relationships and sex. These participants also reflected on the normalising effect of employing support workers of a similar age to their sons and daughters, as this allowed for a more "normal" dating experience by setting up double dates and, as illustrated below, offered the individual with ID an opportunity to learn from a more able peer when navigating romantic relationships: *"I've got one (carer) who is exactly the same age as her and it almost looks like a friend. So I believe that now they are talking about boyfriends and stuff like that (laughs), which is very good"* (Participant 2)

Even those who had not utilised any external supports for relationships or sex specifically, stated that they felt confident that support would be available if it was required: *"I probably would discuss it with his social worker. He's got an excellent social worker, she's very very good. And perhaps ask her if she knows of any groups that we could perhaps go along to and discuss it with"* (Participant 4)

5.5. “Exploring personal meaning and hope”

Participants reflected on the personal meaning relationships held for them and the several meanings they attached to their children’s involvement in relationships. Participants shared their hopes from their sons’ and daughters’ romantic lives, however at the same time acknowledged that they might need to come to terms with the fact that their hopes might be realistically unachievable and might therefore never materialise.

5.5.1. “The way we are meant to be: Exploring the meaning of relationships”

All participants talked about their personal views on relationships and the value of relationships in life. Their narratives implied that relationships were viewed as a natural part of life and the way we are “meant to be”, suggesting that they were essential for happiness: *“I think it's important to have relationships. I think that's the key to everything and even being happy. Because you know that's how we are meant to live is being in relationships with people” (Participant 1).*

Participants’ accounts also suggested that they attached several different meanings to their sons or daughters being involved in a romantic relationship. For some participants this related to the personal meaning of knowing that their child could do what is “normal” or expected at their age: *“Just to be the same as everybody else, to make a choice “would I like to go out with that boy? Would I enjoy going out with him?” (Participant 8).* This view of involvement in romantic relationships as being the norm is perhaps unsurprising given that throughout their narratives, participants often expressed feelings of loss and disappointment in what their children might not be able to achieve. For others, relationships were viewed as an opportunity for social interaction and company. Some participants reflected on the fact that a romantic partner could take up a caring role and continue to provide care and company when they are no longer here: *“I would hope really that she would have somebody to share her life with because I'm not going to be here forever and I would like her not to be lonely” (Participant 3)*

5.5.2. "Hoping they can manage it one day, but probably not sexual"

Participants spoke about their hope that their sons and daughters would in the future be able to have a fulfilling relationship and live with a partner. In their majority, however, they viewed this as a romantic but limited to non-sexual relationship, and attributed this to their perception of their sons and daughters as either not having an interest in a sexual relationship or not being cognitively able to comprehend what this would entail: *"I would like her to meet a nice guy just like her, a genuinely nice person that's kind and would take care of her in so far as, maybe not sexually, I don't know if she could cope with that, but just a nice friendship. A good friend, more of a friend than a boyfriend. I don't actually ever see her in a sexual relationship to be fair. I don't think she has the understanding. I don't see it" (Participant 9)*

Participants frequently spoke about their hope that a long-term partner would be of a similar level of ability and that as partners they would be able to enjoy a friendship and perhaps live together semi-independently and look after each other. For several participants, a long-term friendship was viewed as an appropriate alternative to a romantic relationship. Their narratives often reflected concerns about their children growing older alone and perhaps unsurprisingly, this was a theme predominantly raised by those participants whose sons and daughters were in the older age group. Some participants expressed a hope that their sons and daughters might be able to get married. There was, however, a general sense that having children was not viewed as a plausible outcome. Although only one participant stated this explicitly, most participants generally made no reference to pregnancy and parenthood unless this was in the context of the female's vulnerability.

5.5.3. "Something that I miss for her, that she's never missed"

Participants' accounts revealed feelings of sadness arising from the realisation that their sons and daughters might never be able to be in a long-term relationship. Some

participants talked about the need to prepare themselves for this reality. Understandably, for many participants this was a very emotive topic and one that they found so difficult to discuss openly, that they often avoided thinking about. *"We watched that dating thing, I don't know if you know it, the "Undateables". So we've watched that and I don't think that it could happen for Olivia. That's the sad thing and I've got to be prepared that that's going to be the way it is"* (Participant 2)

Across some participants' accounts there seemed to be an emerging theme of questioning if involvement in relationships was more of a priority for them than it might be for their sons and daughters. As illustrated in the following extract, these participants reflected on their own hopes and expectations of how a life should be lived or what represents a fulfilling life, and in some cases expressed a hope that their children might be able to experience what they had experienced from their own relationships. This naturally led to a realisation that their sons and daughters might not necessarily share this view: *"And that's the part I'm sorry about because... I don't mean you're not complete if you've not had a romantic relationship... but she feels complete in her life, her life is totally, she doesn't seem to want anything else because everything she wants she gets (...) Yeah. It's something that I miss for her, that she's never missed"* (Participant 8). For some participants, this seemed to lead to an acknowledgement of the fact that they would need to let go of that expectation and focus on what really matters to their sons and daughters, regardless of whether that is a relationship or not: *"And I think maybe I do push and I do want that to be going on but I still would want him to be happy, you know and I think if that's what he wants that's fine"* (Participant 1)

6. Discussion

Participants' accounts were consistent with evidence from previous research suggesting that individuals with ID experience romantic interest and desire, and usually have some relationship experience [34, 35]. In this study, participants spoke favourably about their

children's couple relationships and described taking on an active role in practically facilitating and maintaining these [36], providing advice [19, 37] and emotionally supporting their children with relational difficulties [36]. In line with previous research [22], mothers acknowledged experiencing some feelings of discomfort related to the intensity and frequency of their involvement in their children's relationships and, in some cases, this was managed by passing on that role to support staff [29]. In this study, participants reported several perceived barriers to their children's couple relationships, mostly resulting from their cognitive limitations and difficulty understanding social rules and reciprocity, a finding that is consistent with previous research [29]. Although professional input was described as helpful and valuable, there was an acknowledgement that in most cases this was provided in response to an identified problem in relation to sexuality and relationships, reflecting a commonly reported tendency for professional support to be reactive as opposed to preventative [34].

In this study, participants' accounts revealed a conflicting discourse of acknowledging the couple relationships their children had been able to form yet questioning if these were truly 'romantic' in nature. Although in Neuman's [29] study, parents emphasised the physical aspects of their children's couple relationships, in the present study participants generally described the low levels of physical intimacy observed within their children's relationships as a factor compromising their 'romantic' nature. In both studies, however, there was a general sense that participants tended to underestimate the level of emotional and social reciprocity within their children's relationships and the potential of these relationships to meet social and emotional needs as opposed to simply satisfying a desire to be perceived as 'normal' [29]. Research amongst individuals with ID shows that they perceive romantic relationships as meeting a range of emotional and social needs, such as companionship, support, love and care [7, 8], as well as representing a route to achieving a socially recognised 'adult' status [34]. Combined, the above findings suggest

that the nature of individuals' romantic experiences is likely to be multidimensional and that family caregivers may underestimate its subtle complexities.

In contrast to the historical view of individuals with ID as asexual, in this study participants described their sons and daughters as sexual beings, who experienced sexual arousal and curiosity, and in some cases engaged in masturbation, albeit with limited levels of efficacy. Almost all participants, however, identified significant gaps in their sons' and daughters' sexual knowledge, a finding that is widely consistent with previous research [10, 35, 38]. Remarkably, most participants reported having had limited in-depth conversations about sexuality with their children. This was mostly due to a perception that their sons and daughters would have not been interested or able to understand the topic [15], as well as an expectation that they would initiate such conversations if they wanted to find out more [19]. Such an expectation, however, may not always be realistic, especially given research showing that individuals with ID often deny their own sexuality and perceive sex to be a topic that should not be talked about [38].

Of note is that, when participants reported having had some conversations about sex, these tended to focus primarily on personal space and risks, as opposed to promoting positive sexual behaviours [15]. Given the stark contrast between the extensive support mothers provided regarding non-sexual aspects of romantic relationships and the limited conversations about sexual education, it is possible that sexual and contraceptive education was not viewed as necessary unless the individual was involved in a sexual relationship. The risk, however, of withholding conversations about sexuality until it becomes an issue, is that individuals with ID often engage in sexual activities without the knowledge of family carers [12] and may therefore enter relationships with insufficient or inaccurate knowledge [12, 39].

Perhaps unsurprisingly, participants' accounts revealed the dilemmas they experienced between protecting their children from risks whilst supporting them to experience fulfilling

relationships and love. Such findings are likely reflective of the wider debate around how capacity to consent to sexual contact is established in adults with ID [40,41] and the implications this complex issue has for decisions surrounding adult protection and individuals' right to self-determination [42, 43]. The balancing act of needs and rights as opposed to vulnerability and protection is also at the heart of the sexuality and ID literature and represents the most common difficulty faced by both family [19, 22, 24] and paid caregivers [19, 44]. Most participants recognised their children's rights to sexual expression and described a sexual life as a goal their sons and daughters might be able to achieve. These discussions however revealed a more complex picture, as sex was described as being conditional upon certain factors, such as in the context of a 'serious' relationship with the 'right' person. Similar themes have been previously identified by research with staff, who described sex as possible but only in the context of a relationship [45] and parents, who described sex as possible when their children were 'ready' [29].

In line with previous research [23], participants also highlighted that if a relationship became sexual this would require a degree of monitoring, which however was not discussed as necessary in relation to lower levels of intimacy, such as kissing and cuddling. These findings are broadly consistent with reports from individuals with ID, who identify family input as a support as well as a barrier to their sexuality [7, 13], and often report caregiver practices that are perceived as restrictive [12, 28, 38, 35, 46].

Several gender specific concerns were highlighted when participants discussed risk. Females were widely described as requiring more supervision and protection than males, a belief that participants primarily attributed to the risk of pregnancy. The main fear expressed in relation to male sexuality was that of men with ID accidentally crossing a boundary due to their limited understanding of consent. This view of females as potential victims and males as potential perpetrators is perhaps grounded on stereotypical perceptions of males with ID as more sexually impulsive and driven by sexual desires when entering relationships [47, 48] and of women as innocent, naïve and driven by a

need for emotional connection [48]. Such gendered messages are likely to be communicated to individuals with ID either through sex education [49] or through parental attitudes [16] and subsequently reinforce misconceptions regarding gendered roles and influence the way individuals with ID approach relationships.

Participants in this study expressed a sense of investment in their children's ability to find a long-term partner, and on several occasions expressed feelings of sadness arising from the realisation that this might not be possible. Mothers reflected on the value of a life companion and in some cases expressed a hope that a partner would be able to look after their children when they would no longer be able to care for them. The majority of participants viewed long-term relationships as more likely to be non-sexual relationships or friendships due to their children's perceived cognitive and social limitations, which would make a long-term intimate relationship unmanageable [22]. Although this was not the focus of the present study, the topic of pregnancy and the future possibility of parenthood were remarkably absent from participants' accounts unless discussed as a prospect that needed to be avoided [23] or in the context of female vulnerability [49]. Neuman [29] similarly concluded that parents did not consider parenthood as a right or a possibility from their children's lives. Such findings may suggest that, although some progress has been made in relation to rights to relationships and sexuality, the topic of parenthood remains highly controversial and difficult to explore.

As the sample of this study was small and no formal comparisons on the basis of participant characteristics were made, it is not possible to draw conclusions regarding their potential interaction with this study's findings. Nevertheless, certain trends were observed within the data set. For example, mothers of individuals with ID and ASD tended to make reference to greater barriers with regard to reciprocity in relationships, which are likely to be related to the specific deficits in social reciprocity and communication that characterise ASD [50]. This is consistent with previous research showing that, despite a desire to engage in romantic relationships, individuals on the autistic spectrum often

display poor romantic functioning [51]. Mothers of older individuals were more likely to report that their children expressed a desire to live independently, get married and, in some cases, have a family, which, consistently with previous research findings [28], was attributed to witnessing relatives of a similar age achieving those milestones. Mothers of older individuals were also more likely to report negative emotions associated with the possibility of their children never managing a long-term romantic relationship. As these participants were also older in age compared to the rest of the sample, this trend is perhaps reflective of their wider concerns regarding the care and well-being of their children when they would no longer be able to look after them, which is a commonly reported worry by ageing family carers [52].

6.1. Study Limitations

Although this study did not recruit from services focusing on dating and relationships in an attempt to mitigate the risk of systematic bias, a degree of self-selection bias could have impacted on the findings. For example, it is possible that mothers who felt comfortable about participating in the study were those who recognised and valued the need for promoting the rights of individuals with ID to relationships and sexuality. Nonetheless, there was a wide spectrum of conservative and liberal viewpoints represented in the sample, suggesting a degree of diversity amongst participants. Furthermore, although the findings of this study shed further light on issues previously identified by quantitative research, the use of a small convenience sample of participants attending social groups in a specific geographical area means that these are unlikely to be representative of the experience of this population overall. Finally, due to the strict timeframe for the completion of this study, opportunities for triangulation were limited. Although participants' views on produced themes were sought, only one participant provided feedback on the findings. Nevertheless, quality was continually monitored through ongoing reflection and the review of samples of transcripts and emerging themes by a second researcher during data analysis.

6.2. Value and Implications for Research and Practice

The present study provides some valuable evidence in relation to the way mothers of individuals with ID perceive and experience the romantic and sexual lives of adults with ID. In contrast with the majority of previous studies, the inclusion of mothers of both younger and older individuals and the focus on sexual, as well as emotional and social aspects of relationships, allowed for the exploration of issues related to the parental role in the longer-term management of individuals' romantic experiences, the ongoing challenges in relation to autonomy and protection, and maternal perceptions and hopes regarding the future potential of their sons' and daughters' relationships. Some of the themes raised by this study, such as the role of gender in relation to parental perceptions of vulnerability and the distinction often made by participants between the romantic and sexual nature of relationships, with the latter being viewed as more difficult to support, have not been commonly reported by previous research. Considering the potential impact of such views on sexual education provision as well as on how supported and validated individuals may feel by their families to pursue romantic relationships, these issues are certainly worth exploring further by future research.

As the present study focused only on the experiences and perceptions of mothers, the role of fathers was not captured. There were indications across participants' accounts that fathers may hold more conservative views towards their children's romantic and sexual lives or get involved with specific aspects of their socio-sexual education, such as teaching their sons about masturbation. The role of fathers specifically remains largely unexplored by research and it may therefore be worth investigating further in order to allow for their own contributions to the romantic and sexual lives of individuals with ID to be highlighted. Furthermore, although the issue of parenthood was not explored in any depth by this study, the present findings suggest that it continues to remain a taboo topic that families avoid discussing openly. Existing research with staff [53] and parents [29] has provided some preliminary evidence showing that the reproductive rights of

individuals with ID continue to be under-recognised. Given the reported frequency and intensity of parental involvement in the romantic and sexual lives of adults with ID, further research into how reproductive rights and parenthood are perceived and managed by family carers is essential.

Perhaps the most important finding of the present study, with the most significant implications for practice and policy, was the general lack of sexual education reported by participants. Findings suggest that sexual education provided within the school environment was generally not viewed as sufficient, and most participants lacked the confidence to proactively support their children to develop more in depth sexual knowledge. Findings also implied that, although professional support was considered easily accessible, this was reactive in nature and only sought in response to problematic situations. Such conclusions confirm findings of existing research showing that individuals with ID often enter relationships ill prepared and with poor socio-sexual knowledge [12], and highlight the importance of providing timely training to family caregivers to enhance their ability and confidence in supporting their children with such matters. Based on this study's findings, it is essential that such programmes emphasise both protection from risk as well as positive sexual behaviours, and are designed with the influence of potential stereotyped gendered messages in mind.

7. Conclusion

Despite its limitations, the present study made a valuable contribution by allowing mothers' voices to be heard and highlighting both the positive and the challenging aspects of their experience. Research has evidenced that there is still a long way to go until the rights of individuals with ID to romantic and sexual expression are truly recognised and supported within our society. It is hoped that the present study has taken a positive step in that direction, by highlighting the lived experiences and needs of the support systems

around individuals with ID in relation to that sphere of their lives, and inspiring future research and support provision.

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Appendices

Appendix 1: Author Guidelines for Sexuality and Disability

Editorial procedure

Double-blind peer review

This journal follows a double-blind reviewing procedure. Authors are therefore requested to submit:

- A blinded manuscript without any author names and affiliations in the text or on the title page. Self-identifying citations and references in the article text should be avoided.
- A separate title page, containing title, all author names, affiliations, and the contact information of the corresponding author. Any acknowledgements, disclosures, or funding information should also be included on this page.

Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Please ensure you provide all relevant editable source files. Failing to submit these source files might cause unnecessary delays in the review and production process.

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Title Page

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- A concise and informative title
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author

- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

General Manuscript Guidelines

All manuscripts should be in English. All manuscript pages (including figure-caption list, tables, and References list) should be double-spaced and use generous margins on all sides. Manuscripts should be checked for content and style (correct spelling, punctuation, and grammar; accuracy and consistency in the citation of figures, tables, and references; stylistic uniformity of entries in the References section; etc.). Empirical articles should include standard sections, such as Introduction, Methods, Results, and Discussion.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

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Please use no more than three levels of displayed headings.

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Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols. Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

References

Citation

Reference citations in the text should be identified by numbers in square brackets. Some examples:

1. Negotiation research spans many disciplines [3].
2. This result was later contradicted by Becker and Seligman [5].
3. This effect has been widely studied [1-3, 7].

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

The entries in the list should be numbered consecutively.

- Journal article

Hamburger, C.: Quasimonotonicity, regularity and duality for nonlinear systems of partial differential equations. *Ann. Mat. Pura Appl.* 169, 321–354 (1995)

- Article by DOI

Sajti, C.L., Georgio, S., Khodorkovsky, V., Marine, W.: New nanohybrid materials for biophotonics. *Appl. Phys. A* (2007). <https://doi.org/10.1007/s00339-007-4137-z>

- Book

Geddes, K.O., Czapor, S.R., Labahn, G.: *Algorithms for Computer Algebra*. Kluwer, Boston (1992)

- Book chapter

Broy, M.: Software engineering — from auxiliary to key technologies. In: Broy, M., Denert, E. (eds.) *Software Pioneers*, pp. 10–13. Springer, Heidelberg (2002)

- Online document

Cartwright, J.: Big stars have weather too. IOP Publishing PhysicsWeb.
<http://physicsweb.org/articles/news/11/6/16/1> (2007). Accessed 26 June 2007

Always use the standard abbreviation of a journal's name according to the ISSN List of Title Word Abbreviations, see [ISSN.org LTWA](http://www.issn.org/LTWA)

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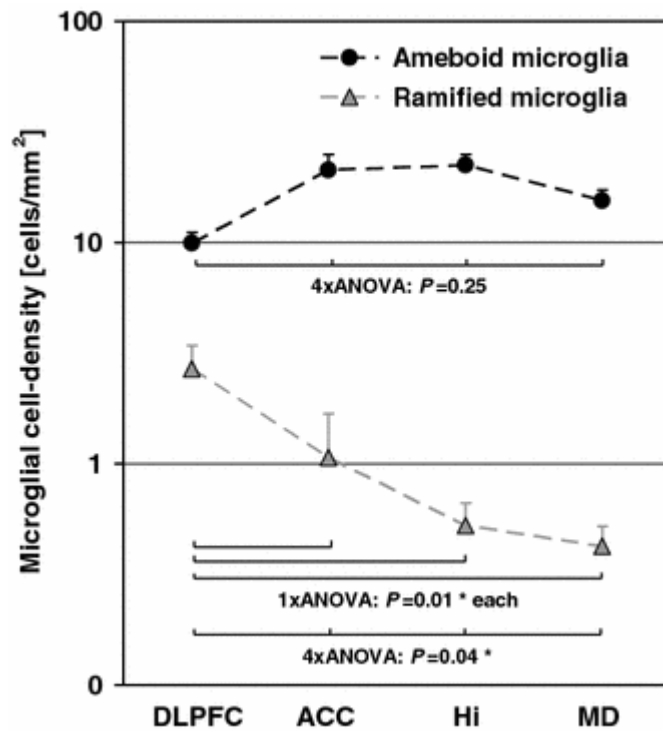
- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
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Artwork and Illustrations Guidelines

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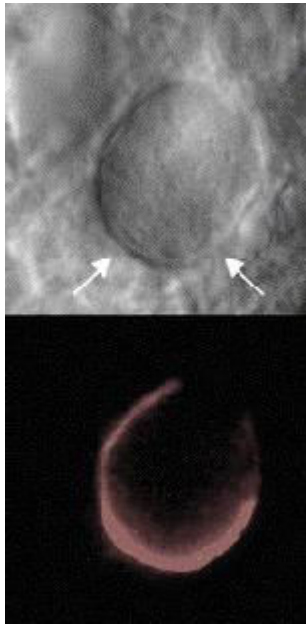
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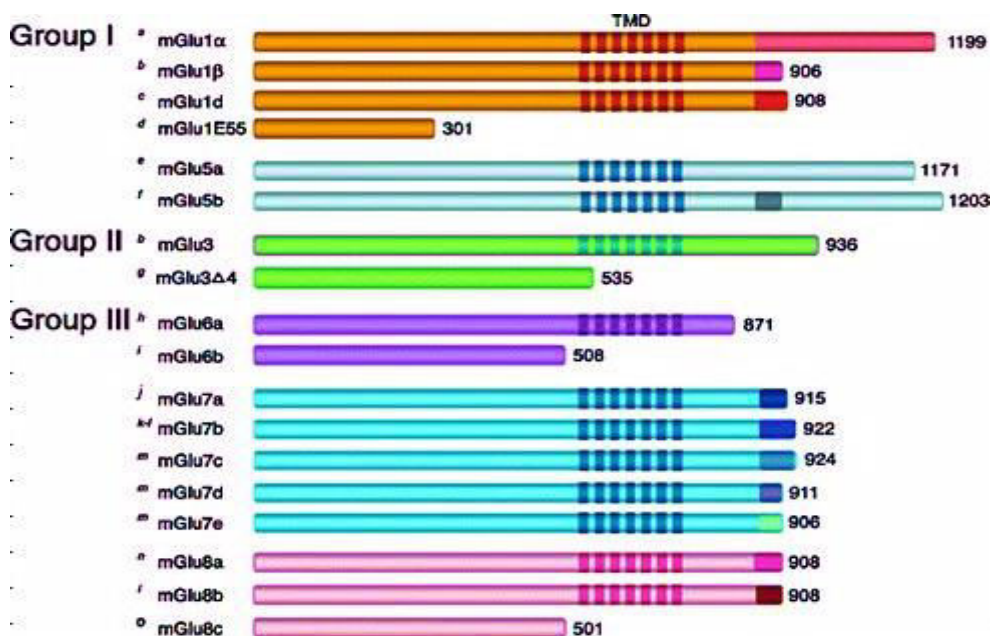
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- Aspect ratio: 16:9 or 4:3
- Maximum file size: 25 GB
- Minimum video duration: 1 sec
- Supported file formats: avi, wmv, mp4, mov, m2p, mp2, mpg, mpeg, flv, mxf, mts, m4v, 3gp

Text and Presentations

- Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.
- A collection of figures may also be combined in a PDF file.

Spreadsheets

- Spreadsheets should be submitted as .csv or .xlsx files (MS Excel).

Specialized Formats

- Specialized format such as .pdb (chemical), .wrl (VRML), .nb (Mathematica notebook), and .tex can also be supplied.

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- It is possible to collect multiple files in a .zip or .gz file.

Numbering

- If supplying any supplementary material, the text must make specific mention of the material as a citation, similar to that of figures and tables.
- Refer to the supplementary files as “Online Resource”, e.g., “... as shown in the animation (Online Resource 3)”, “... additional data are given in Online Resource 4”.
- Name the files consecutively, e.g. “ESM_3.mpg”, “ESM_4.pdf”.

Captions

- For each supplementary material, please supply a concise caption describing the content of the file.

Processing of supplementary files

- Electronic supplementary material will be published as received from the author without any conversion, editing, or reformatting.

Accessibility

In order to give people of all abilities and disabilities access to the content of your supplementary files, please make sure that

- The manuscript contains a descriptive caption for each supplementary material
- Video files do not contain anything that flashes more than three times per second (so that users prone to seizures caused by such effects are not put at risk)

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For editors and reviewers to accurately assess the work presented in your manuscript you need to ensure the English language is of sufficient quality to be understood. If you need help with writing in English you should consider:

- Asking a colleague who is a native English speaker to review your manuscript for clarity.
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Appendix 2: CASP Quality criteria checklist



CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider
 • what was the goal of the research
 • why it was thought important
 • its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider
 • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
 • Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider
 • if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:	
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5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
 - If the researcher has discussed saturation of data

Comments:	
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6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:	
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Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:	
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8. Was the data analysis sufficiently rigorous?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
 - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 3: Systematic Review Excluded articles with Reasons

Study	Reason for Exclusion
1. Grieve, A., McLaren, S., Lindsay, W., & Culling, E. (2009). Staff attitudes towards the sexuality of people with learning disabilities: a comparison of different professional groups and residential facilities. <i>British Journal of Learning Disabilities</i> , 37, 76-84.	Not qualitative
2. Parchomiuk, M. (2012). Specialists and sexuality of individuals with disability. <i>Sexuality and Disability</i> , 30(4), 407-419.	Not qualitative
3. Chapman, J. W., & Pitceathly, A. S. (1985). Sexuality and mentally handicapped people: Issues of sex education, marriage, parenthood, and care staff attitudes. <i>Australia & New Zealand Journal of Developmental Disabilities</i> , 11, 227-235.	Not qualitative
4. Drummond, E. (2006). Attitudes towards sexuality: a pilot study in Ireland. <i>Learning Disability Practice</i> , 9, 28-34	Not qualitative
5. Brown, R. D., Pirtle, T., Brown, R.D. et al. (2008). Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: Examining beliefs using a Q-methodology approach. <i>Sex Education</i> , 8, 59-75.	Not qualitative
6. Schaafsma, D., Kok, G., Stoffelen, J., Van Doorn, P., & Curfs, L. (2014). Identifying the important factors associated with teaching sex education to people with intellectual disability: A cross-sectional survey among paid care staff. <i>Journal of Intellectual & Developmental Disability</i> , 39(2), 157–166.	Not qualitative
7. Szollos, A. A., McCabe, M. P. & Szollos, A.A. (1995). The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers <i>Australia and New Zealand Journal of Developmental Disabilities</i> , 20, 205-222.	Not qualitative
8. English, B., Tickle, A., & das Nair, R. (2019). Consensus-based good practice guidelines for clinical psychologists to support care staff in enabling sexual expression in people with intellectual disabilities-A Delphi study <i>Journal of applied research in intellectual disabilities</i> , 33(2), 268-282.	Not qualitative
9. Meaney-Tavares, R. (2012). Staff characteristics and attitudes towards the sexuality of people with intellectual disability. <i>Journal of intellectual & developmental disability</i> , 37, 269-273	Not qualitative
10. Lin, C. (2011). The marital adjustment and support needs of adults with intellectual disabilities in Taiwan <i>Journal of Sexual Medicine, Blackwell Publishing Ltd</i> , 8, 201.	Unpublished research
11. Schaafsma, D. (2019). Somebody to love: Improving the sexual health of people with intellectual disabilities. <i>Journal of Intellectual Disability Research</i> , 63, 862-863.	Unpublished research
12. Azzopardi-Lane, D. (2019). Sexuality education and support in Malta: Breaking down barriers. <i>Journal of Intellectual Disability Research</i> , 63, 863.	Unpublished research
13. Fyson, R. Clawson, R. & McCarthy, M. (2019). Determining capacity to consent to marry. <i>Journal of Intellectual Disability Research</i> , 63, 856.	Unpublished research
14. McCarthy, M., Bates, C., Forrester-Jones, R. & Skillman, K.M. (2019). Dating agencies for adults with intellectual disabilities. <i>Journal of Intellectual Disability Research</i> , 63, 879.	Unpublished research
15. Bratkovic, D. & Pinjatela, R. (2019). Sexual identity, experiences and perspectives of people with intellectual disability. <i>Journal of Intellectual Disability Research</i> , 63, 886.	Unpublished research

16. L.V.G., S. & Elvira, R.I. (2013). Sexual rights and intellectual disability: An approach from the united nations convention on rights of persons with disabilities. <i>Journal of Sexual Medicine</i> , 10, 340.	Unpublished research
17. Sego, A. (2016). Sexuality workplace issues among direct service personnel working with populations who are intellectually disabled in community integrated living arrangements: A case study. <i>Dissertation Abstracts International Section A: Humanities and Social Sciences</i> , ProQuest Information & Learning.	Grey literature
18. Allen, J. D. (2009). Sexual expression and intellectual disability in Connecticut: A qualitative description of staff practices. <i>Dissertation Abstracts International Section A: Humanities and Social Sciences</i> , ProQuest Information & Learning, 69, 3345	Grey literature
19. Marso, K.J., & Marso, K. J. (1996). Sexuality and adults with mental retardation in residential facilities: services provided, perceived staff training needs, and agency policies. <i>Dissertation Abstracts International: Section B: The Sciences and Engineering</i> , Southern Illinois University at Carbondale, 57, 6213	Grey literature
20. Brooks, J. L. (2004). An exploratory study of the epistemological development of mental clinicians working with adolescents exhibiting sexual behavior problems. <i>Dissertation Abstracts International Section A: Humanities and Social Sciences</i> , ProQuest Information & Learning, 65, 1260.	Grey literature
21. Buckles, J. (2017). "We walk that boundary. it's a tightrope." : A grounded theory approach to the experiences of direct support professionals who work with people with intellectual disability and possibly sexualized challenging behavior. <i>Dissertation Abstracts International Section A: Humanities and Social Sciences</i> , ProQuest Information & Learning, 78.	Grey literature
22. Gonzalez-Acquaro, K. (2006). <i>Sexuality education and mental retardation: Workshop effects on teachers' knowledge, attitudes, and self-efficacy beliefs</i> . Teachers College, Columbia University.	Grey literature
23. Bates, C. (2017). Trained staff can help people overcome the barriers they face in intimate relationships. <i>Community Living, C.L. Initiatives</i> , 31, 22-23.	Not peer reviewed
24. Hamilton, C. (2009). 'Now I'd like to sleep with Rachael'-Researching sexuality support in a service agency group home. <i>Disability & Society</i> , Taylor & Francis, 24, 303-315	Case Study
25. Hepper, F., Aziz Channabasavanna, Gardner, M. et al., (1999). 'A woman's heaven is at her husband's feet'? The dilemmas for a community learning disability team posed by the arranged marriage of a Bangladeshi client with intellectual disability. <i>Journal of Intellectual Disability Research</i> , 43, 558-561	Case study
26. Wings-Yanez, N. (2014). Why all the talk about sex? An autoethnography identifying the troubling discourse of sexuality and intellectual disability. <i>Sexuality and Disability</i> , 32(1), 107-116.	Reflective piece
27. Ménoreau, J. S., & Dupras, A. (2014). Supporting the sexuality of the intellectually disabled: How institutional change and vocational training can help. <i>Sexologies</i> , 23(4), e103-e107.	Secondary data analysis
28. Allen, J. D. (2014). Gay, lesbian, bisexual, and transgender people with developmental disabilities and mental retardation: Stories of the rainbow support group <i>Gay, Lesbian, Bisexual, and Transgender People with Developmental Disabilities and Mental Retardation: Stories of the Rainbow Support Group</i> , 1-145	Secondary data analysis
29. Cambridge, P., Carnaby, S., & McCarthy, M. (2003). Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities: A practice and research overview. <i>Journal of</i>	Secondary data analysis

<i>Learning Disabilities</i> , 7(3), 251-266.	
30. Jones, K., Chatterjee, N., Anslow, K. et al. (2014). Helping vulnerable people develop and maintain relationships. <i>Learning Disability Practice</i> , 17, 30-35.	Insufficient reporting of qualitative data
31. Roy, M., Corbett, J., Newton, J. et al. (1993). Women with a learning disability (mental handicap) referred for sterilisation; Assessment and follow up <i>Journal of Obstetrics and Gynaecology, Informa Healthcare</i> , 13, 270-275.	Insufficient reporting of qualitative data
32. Huntley, C. F., & Benner, S. M. (1993). Reducing barriers to sex education for adults with mental retardation. <i>Mental Retardation, American Association on Mental Retardation</i> , 31, 215-220	Insufficient reporting of qualitative data
33. Heyman, B., & Huckle, S. (1995). Sexuality as a Perceived Hazard in the Lives of Adults with Learning Difficulties <i>Disability & Society</i> , 10, 139-155.	Insufficient reporting of qualitative data
34. Eastgate, G., Scheermeyer, E., van Driel, M.L. et al. (2012). Intellectual disability, sexuality and sexual abuse prevention: A study of family members and support workers. <i>Australian Family Physician, Royal Australian College of General Practitioners</i> , 41, 135-139.	Insufficient reporting of qualitative data (staff data not presented separately from parent)
35. David, H.P., Smith, J.D., Friedman, E. et al. (1976). Family planning services for persons handicapped by mental retardation. <i>American journal of public health</i> , 66, 1053-1057.	Insufficient reporting of qualitative data
36. Maia, A. C. B., dos Reis-Yamauti, V. L., Schiavo, R. A. et al. (2015). Teacher opinions on sexuality and sexual education of students with intellectual disability. <i>Estudos de Psicologia (Campinas)</i> , 32, 427-435.	Not in English
37. Thomas, H., Wawrok, S., Klein, S., et al. (2002). Dealing with sexual self-determination and sexual violence in residential-institutions for young people with mental retardation: Report from an on-going study process, 51, 636-652.	Not in English
38. Abbott, D., & Burns, J. (2007). What's love got to do with it?: Experiences of lesbian, gay, and bisexual people with intellectual disabilities in the United Kingdom and views of the staff who support them. <i>Sexuality Research & Social Policy</i> , 4(1), 27.	Focus on different population
39. Schenk, K. D., Tun, W., Sheehy, M. et al. (2018). "Even the fowl has feelings": access to HIV information and services among persons with disabilities in Ghana, Uganda, and Zambia. <i>Disability and rehabilitation</i> , 1-14.	Focus on different population
40. Cudré-Mauroux, A., Piérart, G., & Vaucher, C. (2019). The importance of the relational needs of people with learning disabilities in the promotion of self-determination. <i>British Journal of Learning Disabilities</i> , 47, 174-180.	Focus on different population
41. Bates, C., Terry, L., & Popple, K. (2017). Supporting people with learning disabilities to make and maintain intimate relationships. <i>Tizard Learning Disability Review</i> , 22, 16-23.	Focus on different population
42. White, E. (2000). Empowered or discouraged? A study of people with learning disabilities and their experience of engaging in intimate relationships. <i>British Journal of Occupational Therapy</i> , 63, 270-276.	Focus on different population
43. Flicker, S., Wilson, C.L., Marshall, Z., et al. (2011). Condoms and contradictions: How queer and trans youth labelled with intellectual disabilities navigate safer sex decisions. <i>Canadian Journal of Infectious Diseases and Medical Microbiology</i> , 22, 107-139.	Focus on different population

44. Rohleder, P. & Swartz, L. (2009). Providing sex education to persons with learning disabilities in the era of HIV/AIDS: tensions between discourses of human rights and restriction. <i>Journal of health psychology</i> , 14, 601-610.	Focus on staff working with individuals under 18 (age of young people unspecified)
45. Löfgren-Mårtenson, L. (2008). Love in Cyberspace: Swedish Young People with Intellectual Disabilities and the Internet. <i>Scandinavian Journal of Disability Research</i> , 10, 125-138.	Focus on staff working with individuals under 18 (age of young people unspecified)
46. Rohleder, P., Swartz, L., Schneider, M. & Eide, A. H. (2012). Challenges to providing HIV prevention education to youth with disabilities in South Africa. <i>Disability & Rehabilitation</i> , 34, 619-624.	Focus on staff working with individuals under 18 (age of young people unspecified)
47. Löfgren-Mårtenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. <i>Sexuality and Disability</i> , 22, 197-207.	Focus on staff working with individuals under 18 (age of young people unspecified)
48. Qian, L. (2017). "Dangerous Adolescence": Sexuality and Disability of Institutionalized Children in a Chinese Orphanage. <i>Sexuality and Disability</i> , 35(4), 445-459.	Focus on staff working with individuals under 18
49. Löfgren-Mårtenson, C. & Ouis, P. (2019). 'We need "culture-bridges": professionals' experiences of sex education for pupils with intellectual disabilities in a multicultural society. <i>Sex Education</i> , 19, 54-67.	Focus on staff working with individuals under 18
50. Löfgren-Mårtenson, L. (2009). The invisibility of young homosexual women and men with intellectual disabilities. <i>Sexuality and Disability</i> , 27(1), 21-26.	Focus on staff working with individuals under 18
51. Aderemi, T. J. (2014). Teachers' perspectives on sexuality and sexuality education of learners with intellectual disabilities in Nigeria. <i>Sexuality and Disability</i> , 32(3), 247-258.	Focus on staff working with individuals under 18
52. Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2011). Conditionally sexual: Men and teenage boys with moderate to profound intellectual disability. <i>Sexuality and Disability</i> , 29(3), 275-289.	Focus on staff working with individuals under 18
53. Swain, J. & Thirlaway, C. (1996). "Just when you think you got it all sorted...": Parental dilemmas in relation to the developing sexuality of young profoundly disabled people. <i>British Journal of Learning Disabilities</i> , 24, 58-64.	Focus on staff working with individuals under 18
54. Wilson, N. J. & Frawley, P. (2016). Transition staff discuss sex education and support for young men and women with intellectual and developmental disability. <i>Journal of Intellectual & Developmental Disability</i> , 41, 209-221.	Focus on staff working with individuals under 18
55. Hanass-Hancock, J., Nene, S., Johns, R., & Chappell, P. (2018). The impact of contextual factors on comprehensive sexuality education for learners with intellectual disabilities in South Africa. <i>Sexuality and Disability</i> , 36(2), 123-140.	Programme evaluation
56. Hames, A. (1996). The effects of experience and sexual abuse training on the	Programme

attitudes of learning disability staff. <i>Journal of Intellectual Disability Research</i> , 40, 544-549.	evaluation
57. Murray, B. L. (2019). Sexual health education for adolescents with developmental disabilities. <i>Health Education Journal</i> , 78, 1000-1011.	Programme evaluation
58. Ward, K. M., Windsor, R., & Atkinson, J. P. (2012). A process evaluation of the Friendships and Dating Program for adults with developmental disabilities: Measuring the fidelity of program delivery. <i>Research in developmental disabilities</i> , 33(1), 69-75.	Programme evaluation
59. Thompson, V. R., Stancliffe, R. J., Wilson, N. J., & Broom, A. (2016). The content, usefulness and usability of sexual knowledge assessment tools for people with intellectual disability. <i>Sexuality and Disability</i> , 34(4), 495-512.	Tool evaluation
60. Wilson, N. J., Cumella, S., Parmenter, T. R., et al. (2009). Penile hygiene: puberty, paraphimosis and personal care for men and boys with an intellectual disability. <i>Journal of Intellectual Disability Research</i> , 53(2), 106-114.	Focus on non-relational aspects of sexual health
61. Carlson, G., & Wilson, J. (1996). Menstrual management and women who have intellectual disabilities: service providers and decision-making. <i>Journal of Intellectual and Developmental Disability</i> , 21(1), 39-57.	Focus on non-relational aspects of sexual health
62. Castell, E., & Kroese, B. S. (2016). Midwives' experiences of caring for women with learning disabilities—A qualitative study. <i>Midwifery</i> , 36, 35-42.	Focus on non-relational aspects of sexual health
63. Brown, H., Hunt, N., & Stein, J. (1994). 'Alarming but very necessary': working with staff groups around the sexual abuse of adults with learning disabilities. <i>Journal of Intellectual Disability Research</i> , 38(4), 393-412.	Focus on risk reduction/sexual abuse
64. Yool, L., Langdon, P. E., & Garner, K. (2003). The attitudes of medium-secure unit staff toward the sexuality of adults with learning disabilities. <i>Sexuality and Disability</i> , 21(2), 137-150.	Focus on risk reduction/ forensic setting
65. Kuosmanen, J., & Starke, M. (2011). Women and men with intellectual disabilities who sell or trade sex: Voices from the professionals. <i>Journal of social work in Disability & Rehabilitation</i> , 10(3), 129-149.	Focus on risk reduction/ forensic setting
66. Phasha, T. N., & Myaka, L. D. (2014). Sexuality and sexual abuse involving teenagers with intellectual disability: Community conceptions in a rural village of KwaZulu-Natal, South Africa. <i>Sexuality and Disability</i> , 32(2), 153-165.	Focus on risk reduction/sexual abuse
67. Starke, M., Rosqvist, H. B., & Kuosmanen, J. (2016). Eternal children? Professionals' constructions of women with an intellectual disability who are victims of sexual crime. <i>Sexuality and disability</i> , 34(3), 315-328.	Focus on risk reduction/ forensic experiences
68. Fish, R. (2016). 'They've said I'm vulnerable with men': Doing sexuality on locked wards. <i>Sexualities</i> , 19(5-6), 641-658.	Focus on risk reduction/ forensic setting

Appendix 4: Excerpt from Thematic Synthesis Coding

Excerpt from Maguire et al. (2019)	Initial Codes
<p>3.1 A Juggling Act</p> <p>All participants described understanding their role as both a facilitator of the individual's goals and aspirations and as a protector of their welfare. They reported wanting to offer support and to help people with issues related to their sexuality while making it clear that they also needed to protect people and manage risk and vulnerability.</p> <p>Their negotiation of these tasks was captured in the theme A Juggling Act. Participant 1 was able to reflect directly on this juggling act, explaining their aim to offer support to the individual while also considering safety and protection. Discussing supporting access to pornography they commented: I would... say you know 'it sounds like this is something you're interested in [watching pornography], it's something you'd like to be doing. It is an adult thing to be doing and looking at and you are an adult now. It's about exploring how to do that in a safe and protected way. (Participant 1)</p> <p>Others were not always explicitly aware of "juggling" but reflected this theme over the course of their interview by fluctuating between expressing facilitative and protective values. Participant 4 expressed strong values related to being a proactive facilitator of sexuality.</p> <p>You see that person not the disability, and you support them to lead the life that they want. (Participant 4)</p> <p>Then later in the interview, noted the importance of safety as paramount. At the end of the day as long as she's safe um, that's all that matters. (Participant 4)</p> <p>This was common across interviews and was interpreted as support workers often needing to hold both roles in mind and having to vary the significance placed on each role dependent on individual service user's needs and the context. This was interpreted as A Juggling Act as it expressed the requirement to manage several things at once, be flexible and quickly adaptable.</p>	<p>Juggling act (protecting vs. facilitating)</p> <p>Sexuality and relationships as source of risk</p> <p>Recognition of role in supporting sexuality/relationships</p> <p>Juggling act (protecting vs. facilitating)</p> <p>Juggling act (protecting vs. facilitating)</p> <p>Sexuality as a right</p> <p>Sexuality and relationships as a source of risk</p> <p>Juggling act (protecting vs. facilitating)</p> <p>Influences on decision making</p> <p>Complexity of role</p>
<p>3.2 There is No Rulebook</p> <p>Participants commented on a range of factors that influenced their perception of their role. The influences and the ways in which support workers drew on these influences were dependent on the situation and context. This communicated a lack of certainty about their role and was interpreted as support workers conveying There is No Rulebook for understanding their role. In practice, this meant they were unable to adopt any routine responses and needed to complete an ongoing evaluation of each individual situation and its influencing factors making sexuality a difficult area to support. Participants commented on personal factors that influenced their perception of their role such as personal beliefs, religion and their work experience.</p>	<p>Influences on decision-making</p> <p>Uncertainty about role</p> <p>Inconsistency of responses</p> <p>Sexuality and relationships as a challenge</p> <p>Own personal beliefs as influencing decisions</p>

<p>That one would be a hard decision for me because I myself am not, I find pornography bad. (Participant 2)</p> <p>Alongside this, they made reference to individual client factors such as age and disability that influenced their thoughts about their role.</p> <p>He's still only young [to watch pornography, age 18]. (Participant 3) My last two placements the learning disabilities were um, more severe than here so, that [sex and relationships] wasn't something I ever thought about. (Participant 5)</p> <p>At an organisational level, training and induction were noted as important. Participant 4 described how the team dynamics and service values could influence the ways in which support workers conceptualized their roles. It's all about the organisation... how you are inducted into the team...sometimes it's quite good to work with younger people that have never, had any experience in care, because you can show them... cos it's quite hard sometimes to change the way the older generation think, and especially when they've been working in these other places. (Participant 4)</p> <p>Participants frequently spoke about feeling unsure of their role in response to the different circumstances outlined in the vignettes. They often stated that they had not experienced these particular situations before. The uncertainty of Participants 3 and 5 was reflected in their hesitation in answering questions and in their comments about having no view about this aspect of their role. Um, I don't know really, I've never, never really thought about it. (Participant 5)</p> <p>Participant 1 appeared to show an acceptance of uncertainty being inherent in the role.</p> <p>When you're working with learning disabilities you have got to expect the unexpected to some degree. (Participant 1)</p>	<p>Client severity of ID or other personal qualities</p> <p>Client severity of ID or other personal qualities</p> <p>Training and support for staff as necessary</p> <p>Service ethos/ policies as an influence</p> <p>Changing attitudes</p> <p>Uncertainty about role</p> <p>Hesitation answering questions/ uncertainty</p> <p>Uncertainty about role</p>
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Appendix 5: Codes Produced from Thematic Synthesis Coding

<p>Sexuality as a right</p> <p>Sexuality and relationships as enhancing quality of life and serving range of needs</p> <p>Sexuality and relationships as a source of risk</p> <p>Sexuality and relationships as a challenge</p> <p>Questioning relationships between sexual behaviour and sexual identity</p> <p>Appropriate vs. inappropriate behaviour</p> <p>Recognition of role in supporting relationships and sexuality</p> <p>Juggling act (protecting vs. facilitating)</p> <p>Hesitation answering questions (uncertainty)</p> <p>Relationships of people with ID as challenging</p> <p>Staff experiencing frustration when clients' needs restricted</p> <p>Avoiding dealing with sexuality directly</p> <p>Avoiding raising sexuality unless initiated by service user</p> <p>Certain aspects of sexuality viewed less favourably (homosexuality)</p> <p>Certain aspects of sexuality viewed less favourably (reproduction)</p> <p>Uncertainty about role</p> <p>Fear of getting in trouble/ repercussions/ powerlessness</p> <p>Influences on decision making</p> <p>Role as not long-term</p> <p>Sexuality outside staff role skillset</p> <p>Lack of training</p> <p>Changing attitudes</p> <p>Inconsistency of responses across staff</p> <p>Staff training focussed on abuse prevention</p> <p>Lack of support from seniors</p> <p>Complexity of role</p> <p>Not using or being aware of educational resources</p> <p>Lack of collaboration between staff and agencies</p> <p>Lack of policy</p> <p>Lack of explicit statement in funding agreements</p> <p>Responding in the heat of the moment</p> <p>No knowledge of policy guidelines</p> <p>Value of policy</p> <p>Seeking support and guidance from other staff/seniors</p> <p>Service ethos/ policies as an influence</p> <p>Practical restrictions in organisations</p> <p>Restrictions posed by other staff imposing own moral judgments</p> <p>Community attitudes</p> <p>Role of family caregivers</p> <p>Own personal beliefs as influencing decisions</p> <p>Client gender</p> <p>Client severity of ID or other personal qualities</p> <p>Service users; poor knowledge and cognitive limitations</p> <p>Culture/ Religion</p> <p>Support perceived as intrusive by clients</p> <p>Reactive responses/ conflict and crisis</p> <p>Support for clients</p> <p>Training and support for staff as necessary</p> <p>Sex/ relationships education as necessary</p>	<p>Attitudes towards sexuality and relationships: A right and a challenge</p> <ul style="list-style-type: none"> -A right and a universal need -A problem and a source of risk <p>Responding to sexuality and relationships: A conflicted discourse</p> <ul style="list-style-type: none"> -Supporting sexuality and relationships -Keeping sexuality and relationships at a distance <p>Uncertainty and lack of systemic support</p> <ul style="list-style-type: none"> -Lack of clear guidelines and policy -Lack of training and support -Uncertainty about role <p>Influences on decision-making</p> <ul style="list-style-type: none"> -Organisational factors -Fear of responsibility and repercussions -Service user factors -The role of family caregivers
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Appendix 6: Demographic/Additional Information Questionnaire



Mothers of adults with intellectual disabilities: Experiences, perceptions and influences on their children's romantic and sexual lives.

Demographic Information Questionnaire

Q1. What is your age?

.....

Q2. What is your child's age?

.....

Please circle as appropriate

Q3. My child is:

- a. Male
- b. Female

Q4. What best describes your child's level of Learning Disability?

- a. Mild Intellectual Disability
- b. Moderate Intellectual Disability
- c. Not known

Q5. What best describes your child's level of required support?

- a. Fully independent on a day to day basis
- b. Requires some support, but not on a day to day basis
- c. Requires a lot of support on a day to day basis

Q6. What best describes your child's living setting?

- a. Living at family home
- b. Living in shared supported accommodation
- c. Living in own home with support
- d. Living in own home without support

Q7. What best describes your child's current relationship status?

- a. Single
- b. In a relationship
- c. Married
- d. Separated/ Divorced
- e. Widowed/ Widower

Q8. What best describes your child's past relationship status?

- a. I believe that my child has been in a romantic/ sexual relationship in the past
- b. I believe that my child has not been in a romantic/ sexual relationship in the past

Appendix 7: Interview Schedule



Mothers of adults with intellectual disabilities: Experiences, perceptions and influences on their children's romantic and sexual lives.

Interview Schedule

1. How would you describe your views on romantic/ sexual relationships in general?

E.g. how would you describe your views on co-habiting/ sexual relationships before marriage?
Have your views changed at all over time? What are they currently and what were they when your son/daughter was younger? What has influenced these beliefs?

2. Can you tell me about the romantic/ sexual relationships your son/daughter has had (if any)?

What has good or bad about them? Are they or have they been different to these of others e.g. sibling? Are there any barriers/ facilitating factors?

3. Do you think that you or other family members influenced your son/daughter's opportunities for relationships or sexual expression?

How involved do you feel? Has your role changed at all over the years?

4. What do you think your son/daughter feels about the relationships they've had/ are in/ haven't been able to get?

Do you think their views would be similar or different to yours or those of other family members?

5. What would you say are your fears in terms of your son/ daughter's romantic life or sexual expression?

What might be a worry when thinking about your son/daughter being in a romantic and/or sexual relationship?

6. What would you say are your hopes in terms of your son/ daughter's romantic life?

What would be the ideal scenario when thinking about your son/daughter's romantic life?

7. What kind of support have you or your son/daughter had in terms of romantic or sexual relationships?

What has helped you to cope with challenges? Is there anything you have found unhelpful?

8. Is there anything else you want to tell me, or you think I should know about relationships and people with intellectual disabilities?

Appendix 8: University of Edinburgh REC Approval Letter



SCHOOL of HEALTH IN SOCIAL SCIENCE
CLINICAL AND HEALTH PSYCHOLOGY

The University of Edinburgh
Medical School
Doorway 6, Teviot Place
Edinburgh EH8 9AG

Telephone 0131 651 3969
Fax 0131 650 3891
Email submitting.ethics@ed.ac.uk

Maria Charitou
Trainee Clinical Psychologist
School of Health in Social Science
University of Edinburgh

08 February 2019

Dear Maria,

Application for Level 2 Approval

Reference: CLIN553

Project Title: Mothers of adults with intellectual disabilities: Experiences, perceptions and influences on their children's romantic lives

Academic Supervisor: Ken MacMahon

Thank you for submitting the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 18th December 2018.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Kirsty Gardner'.

Kirsty Gardner
Administrative Secretary
Clinical Psychology

Appendix 9: University of Edinburgh REC Amendment Approval Letter



SCHOOL of HEALTH IN SOCIAL SCIENCE
CLINICAL AND HEALTH PSYCHOLOGY

The University of Edinburgh
Medical School
Doorway 6, Teviot Place
Edinburgh EH8 9AG

Telephone 0131 651 3969
Fax 0131 650 3891
Email submitting.ethics@ed.ac.uk

Maria Charitou
Trainee Clinical Psychologist
Department of Clinical and Health Psychology
School of Health in Social Science
University of Edinburgh

18 March 2019

Dear Maria,

Ethical Review – Amendment to Project

Reference: CLIN553

Project Title: Mothers of adults with intellectual disabilities: Experiences, perceptions and influences on their children's romantic lives

Academic Supervisor: Ethel Quayle

Thank you for submitting an amendment for the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the amendment has been independently reviewed and was approved on the 9th March 2019.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'K Gardner'.

Kirsty Gardner
Administrative Secretary, Clinical Psychology

Appendix 10: University Ethics Application Form

CPA University of Edinburgh, School of Health in Social Science

RESEARCH ETHICS APPLICATION (REA)



The forms required when seeking ethical approval in the School of Health and Social Sciences have now been merged into this single electronic document. The sections you are required to complete will depend on the nature of your application. Please start to complete the form from the beginning and proceed as guided. On completion the **entire** document should be submitted electronically to your section's ethics administrator using the email addresses detailed on the final page.

FORM OVERVIEW	
FORM	COMPLETION
Project registration form	: Compulsory for all applications
Document checklist	: Compulsory for all applications
Level 1 Self Audit form	: To be completed for all research studies that are not subject to review by an external UK based ethical committee.
Level 2 /3 ethical review form	: To be completed when indicated by responses on the Level 1 form.
Level 4 ethical review form	: applies to research which is potentially problematic in that it may incorporate an inherent physical or emotional risk to researchers or participants, or involve covert surveillance or covert data collection.

PROJECT REGISTRATION FORM

This form is the first stage in applying for University ethical approval and should be completed prior to the commencement of any research project. Applications submitted without appropriate documentation will be returned.

Ethical approval is required for all projects by staff or students conducting research, or similar. Applicants should familiarise themselves with the School's Research Ethics Policy prior to completion.

PR1	Name of Applicant: Maria Charitou
PR2	Name of Supervisor¹: Dr Ethel Quayle
PR3	Project Title: Mothers of adults with intellectual disabilities: Experiences, perceptions and influences on their children's romantic lives.
PR4	Subject Area (section of school): Clinical Psychology
PR5	If student, type of assessed work that this application relates to: DClinPsy Thesis
PR6	Planned date of project submission: March 2020
PR7	Date ethics application submitted:
PR8	(Date complete information submitted if different):
PR9	IRAS Approval Number if applicable: N/A
The following to be completed by ethics administrator	
PR10	Date of initial response to applicant:
PR11	Date of final approval:
PR12	Amendments Requested Date:

¹ Not applicable to staff members.

PR13	Amendments Approved Date:
PR14	Reviewer 1
PR15	Reviewer 2 <i>Level 2/3/4 only</i>
DOCUMENTATION CHECKLIST	

1) ^{DC1} Does your research project require extraction or collection of data abroad? (✓)

<input checked="" type="checkbox"/>	No	If 'No' Skip to Q2	
<input type="checkbox"/>	Yes	Local Ethical review needed, please confirm (✓) electronic attachment of: Application to ethical review panel in country of data collection (in English) + copy of letter of approval	

2) ^{DC2} For the purposes of this research study, will you access identifiable² information on any NHS patient? (✓)

<input checked="" type="checkbox"/>	No	If 'No' Skip to Q3	
<input type="checkbox"/>	Yes	Please confirm (✓) electronic attachment of:	Caldicott Guardian approval for use of NHS data (or confirmation that it is not required)

3) ^{DC3} Does the project require ethical review by an external UK committee e.g. NHS REC or Social Work?

<input checked="" type="checkbox"/>	No	If 'No' Skip to Q4	
<input type="checkbox"/>	Yes	Please confirm (✓) electronic attachment of:	NHS REC (IRAS) /other application form + copy of letter of approval
NOTE: You are <u>not</u> required to complete University ethical review forms. Skip to Q6			

4) ^{DC4} Unless you answered 'yes' to 3, you must also obtain ethical approval through the University of Edinburgh process. Please submit a Level 1 form (with 'Methods' summary) and, if indicated, a level 2/3/4 form as well.

SHSS Ethics paperwork	Forms: level 1	Forms: level 2/3/4	Summary of 'Methods'
Please indicate the SHSS Ethics forms completed herewith (✓):	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	

5) ^{DC5} If you have completed the Level 2/3/4 form please list any additional documentation provided in support of your application (E.g. Disclosure, consent form, participant information, GP letters etc., Data Storage Plan)

Documentation Name <small>These should reflect content</small>	(✓)	Documentation Name	(✓)
Letter of Invitation to Participants V1.2 27 th Nov 2018	✓	Expression of Interest V1.3 27 th Nov 2018	✓
Participant Information Sheet V1.3 27 th Nov 2018	✓	Interview Schedule V1.3 27 th Nov 2018	✓
Poster V1.3. 27 th Nov 2018	✓		
Participant Consent Form V1.3 27 th Nov 2018	✓	Demographic Questionnaire V 1.2 27 th Nov 2018	✓
Information for Services Short V1.2 27 th Nov 2018	✓	Information for Services Detailed V1.2. 27 th Nov 2018	✓

6) Signatures

² 'Identifiable information' refers to information that would allow you to know, or be able to deduce, the identity of a patient. The most common examples of this would be accessing medical records or similar, or accessing a database that includes patients' names.

Maria Charitou	Maria Charitou (Verified by e-mail)	27/08/2018
Applicant's Name	Applicant's Signature	Date signed
Dr Ken MacMahon		24/8/2018
Supervisor³ Name	Supervisor's Signature	Date signed

Please return an electronic copy of your UoE HSS Ethics Application Form (in its entirety) to your Section's Ethics Officer, accompanied by electronic copies of additional documents indicated above. We do not accept paper documentation; please scan all documents into electronic formats. Please keep a copy of all documentation for your records.

LEVEL 1 SELF AUDIT FORM

The audit is to be conducted by all staff and students conducting any type of empirical investigation, including research, audit or service evaluation.

The form should be completed by the principal investigator and, with the exception of staff, signed by a University supervisor.

^{SA1} Primary Research Question:

Please tick	What type of research are you planning to do?
	Study of a novel intervention or randomised clinical trial to compare interventions in clinical practice
✓	Study utilising questionnaires, interviews or measures, including auto-ethnographic data.
	Study limited to working with routinely collected clinical data.
	Meta-analysis or systematic review.
	Research database containing non-identifiable information.

^{SA2} Please provide a brief summary of your proposed study. Our interest is in areas of your methodology where ethical issues may arise so please focus your detail on areas such as recruitment, consent, describing your participants and the nature of their involvement, and data handling.

Project Summary:

This study aims to explore the experiences and perceptions of mothers in relation to the romantic and sexual lives of their adult children (>18) with a mild/moderate intellectual disability using a qualitative design. Participants will be recruited through Third Sector Organisations and any relevant management permissions from organisations that support recruitment will be obtained and evidenced in writing. In order to take part in the study, mothers will need to be fluent English speakers and have capacity to give informed consent.

Following discussion with the researcher, nominated staff employed in Third Sector Organisations will inform potential participants on the aims of the study and distribute participant information leaflets outlining the study aims and procedures. These will outline what participation will entail, give a brief overview of the topics that are

³ Not required for staff applications.

covered by the interview schedule and explain that participation is voluntary. Information posters advertising the study will also be used in order to aid recruitment. Mothers who are interested in taking part in the study will notify nominated staff members and fill out an "Expression of Interest" form to allow for their details (name and phone number) to be passed on to the researcher via e-mail or phone. Alternatively, interested participants can contact the researcher directly using the e-mail address and phone number provided in the information leaflets and posters. During their contact with potential participants, the researcher will provide further information regarding the location, time and duration of the interview and If participants are happy to proceed with the interview, a time and location will be agreed. When meeting with participants prior to the interview, the researcher will answer any questions they might have and will go through the information leaflet with them to ensure they have understood its content. If participants can demonstrate an understanding of what participation will involve and agree to continue, they will be asked to complete the "Consent Form".

Data collection will be conducted using a semi-structured interview, which is expected to last between thirty minutes and one hour. Interviews will take place in community locations, will be recorded using an encrypted audio recording device and will then be transcribed verbatim to aid analysis. Interviews will aim to elicit mothers' perceptions on their offspring's romantic and sexual lives, including perceived needs, influences, advantages and disadvantages, opportunities and barriers, as well as parental fears and hopes. In order to facilitate the interpretation of the data and allow for comparisons within the dataset to be drawn, additional demographic information will be collected. At the end of each interview, participants will be asked if they wish to meet at the stage of data analysis in order to discuss whether the researcher's interpretation provides an accurate representation of their accounts. This will be outlined in the consent form, clearly stating that attendance is voluntary. Participants will also be asked if they wish to receive an accessible summary of the study findings upon its completion via e-mail.

The proposed study will not use a sample of vulnerable adults, however it is possible that carers may disclose information that indicates risk. To mitigate this risk, when consent is taken, participants will be clearly informed about the researcher's duty to disclose information regarding any risk of harm to the participant or risk of harm to others. In the event of a disclosure, this will be managed using clinical judgement and sensitivity. The researcher will discuss risk issues with supervisors and appropriate steps will be taken to safeguard the individuals at risk by following processes consistent with safeguarding vulnerable adults. Should the researcher feel that an individual might be at immediate risk, Social Work services will be contacted as appropriate.

At all stages of data transcription, analysis and write-up, person-identifiable information will be removed, pseudonyms will be used to protect the participants' anonymity and only the researcher and supervising staff will have access to the data. Consent forms will be safely stored throughout the research process in a locked filing cabinet located at the University or at the researcher's Health Board and all data and consent forms will be permanently destroyed after the end of the study.

The researcher will be meeting participants on a one to one basis in organisations and community locations that they will not be familiar with. There is therefore a low level risk related to lone working and violence or aggression. To address these risks, during all contacts with participants the researcher will comply with Lone Working and Violence and Aggression protocols of their NHS Health Board and the University of Edinburgh. More specifically, the researcher will only meet participants at public buildings and will not carry out any home visits. The researcher will become familiar with the building (e.g. exits) prior to meeting participants. All sessions will take place within working hours (Monday to Friday 9am-5pm) and the researcher will ensure that other staff members are close by in the building. The researcher will request to be made aware of any risks or hazards and will ensure that they are known by staff members. The researcher will carry a panic alarm at all times. Prior to meeting participants, the researcher will ask staff members for any relevant information that may indicate risk. The researcher will keep a mobile phone on and will use a call-in system to leave details of sessions with their academic supervisor, including the place

interviews are taking place, the expected end time and relevant contact number.

Please circle your answer as appropriate:

ETHICAL ISSUES		No	Yes
SA3	Bringing the University into disrepute Is there any aspect of the proposed research which might bring the University into disrepute? For example, could any aspect of the research be considered controversial or prejudiced?	No ✓	YES
SA4	Protection of research subject confidentiality <i>Will you make every effort to protect research subject confidentiality by conforming to the University of Edinburgh's guidance on data security, protection and confidentiality as specified in: www.ed.ac.uk/information-services/research-support/data-library/research-data-mgmt</i> <i>For example, there are mutually understood agreements about:</i> (a) non-attribution of individual responses; (b) Individuals, and organisations where necessary, being anonymised in stored data, publications and presentations; (c) publication and feedback to participants and collaborators; (d) With respect to auto-ethnographic work it is recognised that the subject's anonymity cannot be maintained but the confidentiality of significant others must be addressed.	NO	Yes ✓
SA5	Data protection and consent <i>Will you make every effort to ensure the confidentiality of any data arising from the project by complying with the University of Edinburgh's Data Protection procedures (see http://www.ed.ac.uk/information-services/research-support/data-library/research-data-mgmt).</i> For example (a) Ensuring any participants recruited give consent regarding data collection, storage, archiving and destruction as appropriate; (c) Identifying information ⁴ , (e.g. consent forms) is held separately from data and is only accessible by the chief investigator and their supervisors; (e) There are no other special issues arising regarding confidentiality/consent. (f) That where NHS data is being accessed Caldicott Guardian approval has been obtained. IT IS NECESSARY TO GIVE THE HEAD OF SCHOOL'S NAME AS THE CONTACT PERSON IN CASE OF ANY COMPLAINT. PLEASE MAKE SURE THAT THIS LINK IS PROVIDED on any Information sheet/consent form: (http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf)	NO	Yes ✓
SA6	Duty to disseminate research findings Are there issues which will prevent all participants and relevant stakeholders having access to a clear, understandable and accurate summary of the research findings should they wish?	No ✓	YES

⁴ 'Identifiable information' refers to information that would allow you to know, or be able to deduce, the identity of a patient. The most common examples of this would be accessing medical records or similar, or accessing a database that includes patients' names.

- No ☐ (i) Your responses on the completed self-audit confirm the ABSENCE OF REASONABLY FORESEEABLE ETHICAL RISKS.
(ii) Please now read the guidance below and provide the required signatures.
(iii) You are NOT REQUIRED to complete a level 2/3/4 application form.
(iv) Please submit the UoE HSS Ethics Application Form electronic document (in its entirety) along with ALL additional required documentation, failure to do so will mean that your form is returned to you.
- Yes ☒ (i) Your responses on the completed self-audit indicate that we require further information to consider your application.
(ii) Read the Guidance below and provide the required signatures.
(ii) You **ARE REQUIRED** to complete a level 2/3/4 application form.
(III) Please continue to the next part of this document where you will find the level 2/3/4 form

Subsequent to submission of this form, any alterations in the proposed methodology of the project should be reviewed by both the applicant and their supervisor. If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is required.

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

ALL forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

Maria Charitou
Applicant's Name

Maria Charitou (Verified by e-mail)
Applicant's Signature

27/08/2018
Date



*Supervisor Signature⁵

Dr Ken MacMahon
Supervisor Name

24/8/2018
Date

*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all 'No' answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

LEVEL 2/3/4 ETHICAL REVIEW

- Complete only if indicated in the conclusion of your level 1 form.
- Applications will be monitored and audited to ensure that the School Ethics Policy and Procedures are being complied with and applicants contacted in cases where there may be particular concerns or queries.
- Research must not proceed before ethical approval has been granted. For this reason it is particularly important that applications are submitted well in advance of any required date of approval.

⁵ Not required for staff applications

CONFIDENTIALITY AND HANDLING OF DATA	
ER1 What information about participants'/subjects' data will you collect and use?	<p>During the interviews, participants will be invited to discuss their perceptions, needs, experiences, hopes and fears in relation to their children's romantic and sexual lives. Additional demographic information will be collected and this will include; the age of the mother participating in the study, the age and gender of their child, their level of intellectual disability and required support, the child's living setting and the child's current and historical relationship status. This information will be used to present participants during the discussion of the findings and will not be person-identifiable. During the discussion of the study's findings, excerpts from participants' responses will be used to demonstrate links between themes across participants' accounts. Excerpts will be assigned pseudonyms and will not contain any person-identifiable information.</p>
ER2 What is the risk category of the information? (See definitions contained in https://www.ed.ac.uk/infosec/how-to-protect/encrypting/use-cases/short-definition-of-sensitive-data)	<p>High.</p>
ER3 Will the information include any of the following:	<p>(a) racial or ethnic origin (b) political opinions (c) religious beliefs (d) trades union membership (e) physical or mental health (f) sexual life (g) commission of offences or alleged offences</p>
	<p>Details regarding participants' sexual lives are not anticipated to be part of the data collected; however, they may give information regarding the sexual lives of their adult children.</p>
ER4 Who will have access to the raw data?	<p>The researcher, clinical supervisor and academic supervisor will have access to the data. Interview recordings will be securely destroyed following completion of the study. Anonymised transcription data will be securely destroyed five years following completion of the study.</p>
ER5 What training will staff receive on their responsibilities for the safe handling of the data?	<p>All members of the research team are familiar with the Data Protection Act and the University of Edinburgh Guidelines regarding the management of sensitive information. All members of the research team are employed by the NHS and have received formal training on the safe handling of sensitive information within their organisations. Furthermore, the main researcher has completed the relevant sections of the MANTRA online course on research data handling.</p>

ER6 How will the confidentiality of the data, including the identity of participants, be ensured? Is there a strategy in place to replace disclosive identifiers of an individual or entity from the data?

At the stage of data transcription, the researcher will replace participants' names with pseudonyms and all person-identifiable information and contextual references (e.g. locations, occupations etc.) that may identify individuals will be removed to protect their anonymity. A sequential study ID number will be given to each set of data, which can be linked to consent forms with participant identifiable data (in order to facilitate data removal if a participant wishes to withdraw their data from the study after participation). However, consent forms and interview transcriptions will be stored in separate locked cabinets in a locked office on NHS premises or in a locked filing cabinet at the University of Edinburgh.

ER7 Will the information be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

NO If yes, explain why the third party needs to have access to the information and how the transfer of the information will be made secure. Attach a copy of the agreement you will use to regulate the transfer and use of data.

No.

ER8 Describe the physical and IT security arrangements you will put in place for the data.

Data will be collected using an encrypted audio recording device. The audio recording device and consent forms will be safely stored in a locked filing cabinet within NHS premises or at the University of Edinburgh throughout the research process. Electronic documents produced for the purposes of data analysis will not contain any identifiable information and will be stored on a University laptop, which is data encrypted and password protected. Audio files and consent forms will be permanently destroyed after the end of the study.

ER9 Does the system have a security code of practice under the University's Information Security Policy? (see <http://www.ed.ac.uk/information-services/about/policies-and-regulations/security-policies/security-policy>)

YES/NO If NO, explain why one is not needed.

Yes.

ER10 Will the data be used, accessed or stored away from the University premises?

YES/NO If YES, describe the arrangements you have put in place to safeguard the data from accidental or deliberate access, amendment or deletion when it is not on University premises, including when it is in transit.

Following each interview, there will be a need to transport the data (audio recording, consent forms and demographics sheet) to NHS premises or at the University of Edinburgh. In order to maintain data security, the audio recording will be on an encrypted, passcode-protected recorder, with this – and all paperwork – carried in a locked bag. If it is not possible to access NHS premises following an interview (e.g., if later than working day), then the bag may be stored at the researcher's home address. If this is the case, the bag will be stored in the most secure location available in the researcher's home and the data will be taken to NHS premises or to the University of Edinburgh for storage as soon as practicable.

<p>ER11 Specify where the data files/audio/videotapes etc. will be retained after the study, how long they will be retained and how they eventually will be disposed of?</p>	
<p>Audio recordings and consent forms will be securely destroyed, in line with University of Edinburgh data security procedures. Anonymised transcriptions and data files will be retained within the University of Edinburgh for a period of five years.</p>	
<p>ER12 How do you intend for the results of the research to be used?</p>	
<p>This research project is in part fulfilment of the requirements for a Doctorate in Clinical Psychology. The final report will be submitted to the University of Edinburgh as a doctoral thesis. The results of the study will be disseminated to participants and services involved in recruitment. The study may also be presented in conferences and be published in an academic journal.</p>	
<p>ER13 Will feedback of findings be given to participants/subjects?</p>	
YES	If yes, how will this feedback be provided?
<p>Upon completion of the study, an accessible written summary of the main findings will be distributed to the participants who have expressed interest in receiving a summary. The researcher will also design leaflets and posters summarising the study findings and these will be distributed to services and organisations working with adults with intellectual disability/ carers.</p>	
<p>ER14 Using secondary data:</p>	
NO	(a) Is this reuse compatible with what the data subjects were originally told about the use of their data? (e.g. were they told that it would be destroyed at the end of the study?)
NO	(b) Is it likely that someone could be identified from this data? (It is extremely difficult to make something totally anonymous, so even with secondary data there may be a need to apply security and access restrictions to it).
<p>For more information regarding data linkage in evaluating interventions for the benefit of the population's health, please see: http://www.gov.scot/Topics/Statistics/datalinkageframework</p> <p>Your application at this level is likely to require additional documentation, for example a Data Storage Plan, consent forms or participant information sheets. Please return to the Documentation Checklist on page 2 to list your supporting documentation.</p>	
<p>SECURITY-SENSITIVE MATERIAL</p>	

ER15 Does your research fit into any of the following security-sensitive categories? If so, indicate which.

- NO Commissioned by the military
- NO Commissioned under an EU security call
- NO Involve the acquisition of security clearances
- NO Concern groups which may be construed as terrorist or extremist

IF YOU HAVE ANSWERED YES TO ANY OF THESE CONTINUE TO ER16. IF YOU HAVE ANSWERED NO TO ALL OF THESE QUESTIONS MOVE TO ER21.

ER16 The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

- YES/NO Does your research involve the storage on a computer of such records, statements and other documents?
- YES/NO Might your research involve the electronic transmission (e.g. as an email attachment) of records or statements?

IF YOU ANSWERED YES TO ANY OF THESE YOU ARE ADVISED TO STORE THE RELEVANT RECORDS OR STATEMENTS ELECTRONICALLY ON A SECURE UNIVERSITY FILE STORE. THE SAME APPLIES TO PAPER DOCUMENTS WITH THE SAME SORT OF CONTENT. THESE SHOULD BE SCANNED AND UPLOADED.

ACCESS TO THIS FILE STORE WILL BE PROTECTED BY A PASSWORD UNIQUE TO YOU AND YOUR SCHOOL RESEARCH ETHICS OFFICER. PLEASE INDICATE THAT YOU AGREE TO STORE ALL DOCUMENTS RELEVANT TO THESE QUESTIONS ON THAT FILE STORE:

YES/NO

ER17 Please indicate that you agree not to transmit electronically to any third party documents in the document store:

YES/NO

ER18 Will your research involve visits to websites that might be associated with extreme or terrorist organisations?

YES/NO

ER19 If you answer YES to ER18 you are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please acknowledge that you understand this risk:

YES/NO

ER20 By submitting to the research ethics process, you accept that your School Research Ethics Officer and the convenor of the University's Compliance Group will have access to a list of titles of documents (but not the content of documents) in your document store. Please acknowledge that you accept this.

YES/NO

Countersigned by supervisor/manager:

Name:

Date:

RISKS TO, AND SAFETY OF, RESEARCHERS NAMED IN THIS APPLICATION

ER21 Do any of those conducting the research named above need appropriate training to enable them to conduct the proposed research safely and in accordance with the ethical principles set out by the College?

NO

ER22 Are any of the researchers likely to be sent or go to any areas where their safety may be compromised, or they may need support to deal with difficult issues?

NO

ER23 Could researchers have any conflicts of interest?

NO

RISKS TO, AND SAFETY OF, PARTICIPANTS

ER24 Are any of your participants children or protected adults (protected adults are those in receipt of registered care, health, community care or welfare services. Anyone who will have contact with children or protected adults requires approval from Disclosure Scotland at <http://www.disclosurescotland.co.uk/>

Do any of the researchers taking part in this study require Disclosure Scotland approval? (✓)

Not applicable		*Ethical approval will be subject to documentation confirming Disclosure Scotland approval with this form.
Relevant researcher/s has current Disclosure Scotland approval through a current NHS employment contract	✓	
Yes*		

ER25 Could the research induce any psychological stress or discomfort?

YES
ER26 Does the research involve any physically invasive or potentially physically harmful procedures?
NO
ER27 Could this research adversely affect participants in any other way?
Yes. Although it is anticipated that participation in the study will not have any significant harmful effect on the individuals, it is possible that during the interviews participants may experience distress when discussing certain aspects of their children's lives. To mitigate this risk, the possibility of the interview process raising difficult emotions will be clearly stated in the information leaflets and posters. The voluntary nature of participation and participants' right to withdraw from the study at any time will also be explicitly stated in the information leaflets and consent forms. The interview schedule was developed following the researcher's informal contact with carer representatives who will offer their views to ensure the issues explored are appropriate. Following the interview, participants will be offered some time for debriefing and will be given the opportunity to discuss any concerns or difficult emotions triggered by the interview. The researcher will also provide helpline numbers as appropriate.
RESEARCH DESIGN
ER28 Does the research involves living human subjects specifically recruited for this research project <i>If 'no', go to section 6</i>
YES
ER29 How many participants will be involved in the study?
Approximately 14 participants will be recruited, with the anticipation that, due to attrition, approximately 10 – 12 participants will be included in the final sample, given the potential for participants to withdraw consent.
ER30 What criteria will be used in deciding on inclusion/exclusion of participants?
Participants will need to be mothers of an adult aged (>18) and who has a diagnosis of mild/moderate intellectual disability. Mothers who are not fluent in English, or where there are any concerns about their capacity to consent, will not be included in the research. The researcher will use the criteria proposed by the Mental Health Act (2003) to assess participants' capacity to make an informed decision regarding participation. More specifically, in order to demonstrate capacity, participants will need to be able to a) understand the information relevant to the decision, b) retain that information and c) use or weigh up that information as part of the process of making the decision. The researcher will ensure that each participant is given enough time and opportunity to demonstrate the above prior to engaging in the interview process.
ER31 How will the sample be recruited? (E.g. posters, letters, a direct approach- specify by whom.)

<p>Staff working at services involved with carers of adults with intellectual disabilities will be informed on the aims of the study and be given packs containing letters of invitation to participants and information leaflets. Nominated staff members will identify potential participants and distribute participant information leaflets outlining the study aims and procedures. Information posters advertising the study will also be used in order to aid recruitment. Individuals who are interested in taking part in the study will notify the nominated staff members and fill out an "Expression of Interest form" to allow for their details (name and phone number) to be passed on to the researcher. The researcher will not initiate contact with participants unless they have agreed for their details to be passed on to them. Alternatively, interested participants can contact the researcher directly using the e-mail address and phone number provided in the information leaflets and posters.</p> <p>When making contact with potential participants, the researcher will use their university e-mail address and a study-specific phone number for all telephone communications. During their contact with potential participants, the researcher will be available to answer any queries they may have and provide further information regarding the location, time and duration of the interview. If participants are happy to proceed with the interview, a time and location will be agreed. The researcher will meet with participants to discuss any questions they may have and will talk them through the process to ensure that they have a full understanding of what is required for participation. If participants are happy to proceed, their written informed consent will be obtained prior to commencing the interview.</p>
<p>ER32 Will the study involve groups or individuals who are in custody or care, such as students at school, self-help groups, residents of nursing home?</p>
<p>NO</p>
<p>ER33 Will there be a control group?</p>
<p>NO</p>
<p>ER34 What information will be provided to participants prior to their consent? (e.g. information leaflet, briefing session)</p>
<p>YES. There is a written Participant Information Sheet outlining the aims of the study, the research process, what participation involves and confidentiality issues. As well as this being provided to participants prior to them considering taking part, the contents of this sheet will also be reviewed, in person, with the potential participant before consent is taken.</p>
<p>ER35 Participants have a right to withdraw from the study at any time. Please tick to confirm that participants will be advised of their rights, including the right to continue receiving services if they withdraw from the study.</p>
<p><input checked="" type="checkbox"/></p>
<p>ER36 Will it be necessary for participants to take part in the study without their knowledge and consent? (e.g. covert observation of people in non-public places)</p>
<p>NO</p>
<p>ER37 Where consent is obtained, what steps will be taken to ensure that a written record is maintained?</p>
<p>Written informed consent to participate in the study will be obtained prior to the interview. Written consent will also be sought from participants regarding their participation to the review of the themes produced at the stage of analysis. Once consent has been obtained, written records will be safely stored in a locked filing cabinet at the researcher's employing Health Board or at the University of Edinburgh and will remain there until the end of the study. Only the direct research team will have access to written records of consent.</p>

ER38	In the case of participants whose first language is not English, what arrangements are being made to ensure informed consent?
	Due to the methodology employed within this study, only individuals who are fluent in English will be eligible to participate.
ER39	Will participants receive any financial or other benefit from their participation?
	NO
ER40	Are any of the participants likely to be particularly vulnerable, such as elderly or disabled people, adults with incapacity, your own students, members of ethnic minorities, or in a professional or client relationship with the researcher?
	NO
ER41	Will any of the participants be under 16 years of age?
	NO
ER42	Will any of the participants be interviewed in situations which will compromise their ability to give informed consent, such as in prison, residential care, or the care of the local authority?
	NO
BRINGING THE UNIVERSITY INTO DISREPUTE	
ER43	If on the level one form you have answered YES that some aspect of the proposed research "might bring the University into disrepute", please elaborate alongside how this might arise, and what steps will be taken by the researcher to mitigate and/or manage this, to minimise adverse consequences to the University.
	N/A

Subsequent to submission of this form, **both the applicant and their supervisor should review any alterations in the proposed methodology of the project.** If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is **required**.

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

ALL forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

Maria Charitou
Applicant's Name



Maria Charitou (Verified by e-mail)
Applicant's Signature


27/08/2018
Date

Dr Ken MacMahon _____ 24/8/2018 _____

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*Supervisor Signature⁶ Ethel Quayle (new supervisor) 29.10.18
Supervisor Name Date

*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all 'No' answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

ER44 ISSUES ARISING FROM THE PROPOSAL
<p>I can confirm that the above application has been reviewed by two independent reviewers. It is their opinion that:</p> <p>a) The ethical issues listed below arise or require clarification:</p> <p>1. Supervisor</p> <ul style="list-style-type: none">• Main supervisor has now left his lectureship at the university. Do you need to change details to provide new supervisor? <p>2. Participants will be recruited through Third Sector Organisations and any relevant management permissions from organisations that support recruitment will be obtained.</p> <ul style="list-style-type: none">• Evidence of organisation permission required. <p>3. In order to take part in the study, mothers will need to be fluent English speakers and have capacity to give informed consent.</p> <ul style="list-style-type: none">• How will capacity be determined? <p>4. Consent Form</p> <ul style="list-style-type: none">• Some additional points may be relevant (e.g. "I have had the opportunity to <u>ask questions</u> and received <u>satisfactory answers from the researcher</u>", "I understand that this study is not part of my child's <u>support service</u> and will not impact my child's support in any way".) <p>5. Romantic vs sexual relationships</p> <ul style="list-style-type: none">• The ethics application indicates <i>romantic relationships</i> is the concept of interest rather than <i>sexual relationships</i> (although acknowledges that information about sexual relationships may arise from participant responses). Conflictingly, the Information for Services documents and the Participant Information sheet indicate that both types of relationships are under investigation but the Interview Schedule only specifically asks about romantic relationships. It might be worth clarifying this across all documentation. <p>6. Poster – requires additional information (e.g. supervisor contact details).</p> <p>7. Consent and information sheet should be reviewed to ensure GDPR compliance.</p> <p>8. Has sponsorship by University been established?</p> <p>The applicant should respond to these comments in section 8 below.</p> <p>Signature: </p> <p>Position: Lecturer in Clinical Psychology, Ethics Tutor</p> <p>Date: 15/10/18</p>

⁶ Not required for staff applications

ER45 **APPLICANT'S RESPONSE (If required)**

1. The supervisor's name has been changed on the Ethics Application Form and all supporting documents. The new supervisor has countersigned the ethics form.
2. Organisations will be approached and provided with information about the study once the supporting research documents (i.e. Information for Services) have been approved by the University. Permissions from organisations that will express interest to participate in the study will be provided and evidenced in writing once their interest to get involved has been established.
3. Additional information in relation to the assessment of capacity has been added in Section ER30 of this form. This states that "the researcher will use the criteria proposed by the Mental Health Act (2003) to assess participants' capacity to make an informed decision regarding participation. More specifically, in order to demonstrate capacity, participants will need to be able to a) understand the information relevant to the decision, b) retain that information and c) use or weigh up that information as part of the process of making the decision. The researcher will ensure that each participant is given enough time and opportunity to demonstrate the above prior to engaging in the interview process".
4. All suggested additional statements have been added to the consent form.
5. The term "sexual" has been added to the Interview Schedule to facilitate participants to share their views on romantic as well as sexual relationships.
6. Supervisor Contact Details have been added to the Poster.
7. The information sheet and consent form have been reviewed and changes have been made to ensure compliance with GDPR. More specifically, the website information has been added and the contact details of the Data Protection Officer have been provided. The following statement in relation to complaints regarding the management of data has been added: "If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) at <https://ico.org.uk/>."
8. Ms Charlotte Smith, Research Governance Coordinator, has confirmed that sponsorship by the University of Edinburgh will not be required in this case.

Signature: Maria Charitou (Verified by e-mail)

Date: 31/10/2018

ER46 **CONCLUSION TO ETHICAL REVIEW (if required)**

This amendments have generally been responded to in a satisfactory fashion with one exception. The issue of whether the study is about romantic relationships or sexual relationships is still unclear and inconsistently presented in different documents. In the ethics application romantic relationships is stated. The title of the project suggests romantic relationships. The information sheets has the project title with 'romantic relationships' but then goes on to various talk about romantic relationships, sexual relationships, intimate relationships and sex. All quite different. This needs addressing before this project can proceed so that parents do not feel blind-sided after they have signed consent to participate - this is a sensitive topic for many parents and may cause distress if participants feel that they have been deceived.

Signature: Corinne Reid

Position: Reader in Clinical Psychology

Date: 23.11.18

Applicant's response

In order to address this inconsistency, the researcher has changed the title of the project to include mothers' perceptions and experiences in relation to the romantic and sexual lives of their sons and daughters. The term "sexual" has been added next to the term "romantic" across all supporting documents to ensure that the aims of the study are clearly presented to potential participants prior to them providing consent. Updated versions of all supporting documents have been attached and version numbers have been changed in the "Documentation Checklist" section of this form.

ER47 AMENDMENT/S: REQUEST FOR APPROVAL

Subsequent to receipt of ethical approval above, I, the applicant, would like to request the following amendment/s to my original proposal.

ER48 CONCLUSION TO ETHICAL REVIEW OF AMENDMENT

I can confirm that the above amendment has been reviewed by two independent reviewers. It is their opinion that:
a. Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary,



Signature: (Dr. Corinne Reid)

Position: Director of Research and Knowledge Exchange, HiSS

Date: 07.12.18

Following discussion with my supervisor, Dr Quayle, I would like to make an amendment in relation to the method of recruitment used. More specifically, although I will continue to recruit through third sector organisations, where people who are parents of an individual with LD make contact through knowing about the study (snowballing) then I would like to include them in the study provided that they meet the inclusion criteria and are able to give informed consent. In addition, during recruitment I will be sharing the study information with other professionals (e.g. social workers, support workers etc.) employed at locality support services (as well as third sector organisations). I have sought advice from Ms Charlotte Smith regarding this and she has advised that no additional ethical procedures would need to be followed regarding this as I would still not be recruiting from health related organisations.

In addition, during the analysis of transcribed interviews, I intend to use the Dedoose software rather than NVivo as previously stated, as it is felt to be more user-friendly.

Signature: Maria Charitou (verified by e-mail)

Date: 25/02/2019

I can confirm that the above amendment has been reviewed by two independent reviewers. It is their opinion that:
Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary,



Signature:

Position: Lecturer in Clinical Psychology, Ethics & Integrity Lead

Date: 09/03/2019

Acronyms / Terms Used

NHS: National Health Service

SHSS: School of Health in Social Science

Appendix 11: Participant Information Sheet



Mothers of adults with intellectual disabilities: Experiences, perceptions and influences on their children's romantic and sexual lives.

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a study looking at the experiences and perceptions of mothers of adults with intellectual disabilities in relation to their son's and daughters' romantic and sexual lives.

This leaflet is designed to give you information on the study and your participation to help you decide whether you want to take part. If you would like any further information, you can contact me using the details available at the end of this leaflet.

About me

I am a Trainee Clinical Psychologist employed by NHS Lanarkshire and currently studying towards a Doctorate in Clinical Psychology at the University of Edinburgh. I am carrying out this study as part of my doctorate course and I am the lead researcher for this research.

What is the purpose of this study?

We know from research that parents of adults with intellectual disabilities play an important role in helping their children understand relationships and sex, and supporting them with developing relationships. Despite the importance of their role, we only know very little about how parents experience the romantic and sexual lives of their children during adulthood and about their needs in relation to supporting them with their romantic and sexual needs.

This study aims to find out more about the experiences and perceptions of mothers of adults with intellectual disability in relation to their romantic and sexual lives by exploring their attitudes, fears

and hopes, as well as the challenges they may face. Although fathers' experiences are also important, this study will be focusing on mothers as research shows that they tend to be more involved in conversations about sexual and romantic issues. This study will use interviews with mothers of adults with intellectual disabilities, who will be approached through third sector organisations.

Why have I been invited to take part?

You have been invited to take part in the study because you care for an adult with a diagnosis of a mild/moderate intellectual disability.

Do I have to take part?

Participation in the study is voluntary, so it is entirely up to you to decide whether or not to take part. If you decide not to take part this will not affect the services you or your child receives in any way at all. If you decide to take part you will be given this information sheet to keep and you will also be asked to sign a consent form and keep a copy as well.

What will happen if I decide to take part?

If you decide that you want to take part in the study, there are two ways to get in touch with me. You can either ask for your details (e-mail address or phone number) to be passed on to me, or you can contact me directly using the contact details at the end of this leaflet. If you would prefer for your details to be passed on to me, you can ask the service (where you got this information leaflet from) to do this for you. Once I have your details, I will get in touch with you either by phone or e-mail.

During our communication, you will have a chance to ask any questions you may have and if you are happy to continue we will arrange a time and a place to meet. During our meeting, I will give you more information about the study and you will have a chance to ask questions. Before we start the interview, I will ask you to sign a Consent Form to make sure you are happy with what we have agreed. The interview will last between 30 minutes and 1 hour and it will cover areas such as your hopes and fears about your child's romantic life, your needs and in general your experiences around supporting your child with their romantic and sexual life.

If I decide to take part, how many times will we meet?

We will only have to meet once for the interview.

At a later time (end of 2019) I will be looking to meet again with people who have taken part in the study to show them what I have found and ask them to give me their opinions on my results. Attending this second meeting is completely optional. If after the end of the interview you decide that you would not like to come back at a later time to give you opinion on the study's results, this is not a problem and it will not affect your taking part in the study at all.

Will my taking part in the study be kept confidential?

All of your information will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All of your responses will be kept strictly confidential. During the transcription of the interview recordings any information that could identify you will be removed and names will be replaced with pseudonyms. Interview transcripts will be safely stored during the study and only authorised people will have access to them. All interview transcripts will be destroyed after the end of this study. For the preparation of the final report, some quotes from your written responses will be used as examples of the patterns or themes found across all participants' responses. These quotes will not include any identifiable information and will be followed by pseudonyms.

Please note that, although I will aim to protect confidentiality at all times, if any of the information shared during the interviews makes me concerned that you or someone else might be at risk of harm, I will have a duty of care to breach confidentiality. This will involve reporting my concerns to my supervisors and taking appropriate steps to safeguard the individuals involved.

For general information about how we use your data go to:

<https://www.ed.ac.uk/records-management/privacy-notice-research>

What are the possible disadvantages or risks of taking part?

Although it is hoped that participation in the study will not have any significant harmful effect, it is possible that you may find some of the topics we will talk about upsetting. As participation is voluntary, you have the right to not take part if you feel that taking part will be too distressing. If you decide to take part but find that you become distressed during the interview, you can let me know and we can stop at any time. Following the interview, you will be offered some time for debriefing if you feel this can be helpful.

What are the possible benefits of taking part?

You may not get a direct benefit from taking part in this study. However, I hope that developing a better understanding of mothers' perceptions and experiences will allow services to support them and their children in a way that better meets their needs.

What will happen to the results of the study?

After the end of the study, the results will be written up in the form of leaflets and posters that will be given to the services that have been involved in the study. A written summary will also be made available to all mothers participating in the study if they wish to receive one. The study may also be published in an academic journal.

How will I find out the results of the study?

A written summary of the findings can be made available to all participants after April 2020. When we meet, you can let me know if you would like to receive a summary of the findings and if you do, you will be asked to sign a consent form and provide your e-mail address.

What do I do if I have any questions?

If you have any further questions about the study, please contact Maria Charitou at s1373469@sms.ed.ac.uk or Dr Ethel Quayle at ethel.quayle@ed.ac.uk or Dr Alan Sutherland at alan.sutherland@lanarkshire.scot.nhs.uk.

If you wish to speak to someone who is independent of the study, but who can provide further information, please contact: Dr Angus MacBeth, Lecturer in Clinical Psychology, School of Health in Social Science, University of Edinburgh at angus.macbeth@ed.ac.uk or 0131 650 3893.

If you wish to make a complaint about the study please contact Professor Charlotte Clarke, Head of School, School of Health in Social Science, University of Edinburgh at charlotte.clarke@ed.ac.uk or 0131 650 4327.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter.

University of Edinburgh

Data Protection Officer
Governance and Strategic Planning
University of Edinburgh
Old College
Edinburgh
EH8 9YL

Tel: 0131 651 4114
dpo@ed.ac.uk

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) at <https://ico.org.uk/>.

Thank you for your time.

If you would like to find out more about the study, then please fill in the "Expression of Interest" form and return to the Manager of the Organisation or you can contact me directly at s1373469@sms.ed.ac.uk.

Yours sincerely,
Maria Charitou
Trainee Clinical Psychologist

Supervised by:
Dr Ethel Quayle
Senior Lecturer in Clinical Psychology
Clinical & Health Psychology
School of Health in Social Science
University of Edinburgh
Teviot Place
Edinburgh
EH8 9AG
Ethel.Quayle@ed.ac.uk

Dr Alan Sutherland
Clinical Psychologist
Learning Disability Service
Longdales Administration Building
Kirklands Site
Bothwell
G71 8BB

Appendix 12: Participant Consent Form



Mothers of adults with intellectual disabilities: Experiences, perceptions and influences on their children's romantic and sexual lives.

Participant Consent Form

I confirm that I have read and understood the information provided in information sheets for the above study. ☐

I understand that I do not have to take part in this study. Participation is entirely voluntary and deciding not to participate will not have negative consequences on either myself or my child. ☐

I am aware that that my responses will only be used for the purposes of this study, as described in the Information Sheet. ☐

I understand that all information that could identify me will be removed when my interview is transcribed. ☐

I understand that audio recordings of the interview will be made and transcribed and agree to direct quotations from the interview can be included in the final research report. ☐

I agree to take part in the above study. ☐

I have had the opportunity to ask questions and received satisfactory answers from the researcher.

☐

I understand that this study is not part of my child's support service and will not impact my child's support in any way. ☐

I wish to be contacted to arrange a meeting during the analysis of the interviews in order to give my opinion on the results. ☐

I wish to receive a written summary of the results after the end of the study. ☐

If you wish to be contacted to review the results at the stage of analysis and/or receive a written summary of the findings after the end of the study (April 2020), please provide your e-mail address under your signature.

Your details will be safely stored and will only be used for this purpose. Consent forms will be permanently destroyed after the end of the study.

Name of participant Date Signature

Name of researcher Date Signature

Appendix 13: Excerpt of Transcript and IPA Coding

Emergent Themes	Transcript	Exploratory Comments
Relationships as not really romantic	Could you tell me a little bit about the romantic relationships George has been able or not able to get so far?	
Relationships as different and non-normative	Well I wouldn't say they were quite romantic in the true sense of the word, he would say Sarah for instance, he loves Sarah, he will say "I love Sarah, I love Sarah, I love Sarah". Sarah is a girl from school that they went to prom together and they had their photograph taken together and he shakes her hand. And that's about the level of the relationship but he was saying he loves her and that's his girlfriend.	Not "truly" romantic- what makes a relationship truly romantic? Perception of someone being a girlfriend quite basic- implying that level of interaction and intimacy (?) does not qualify this as a relationship
Relationships as childlike or basic	But he's very Primary School, you know. He doesn't have any, there are other girls that he likes, for example there's Jane, another girl that he loves the bits but he wants to shake her hand and he wants to have tea with her. But that's the level of the romance.	Relationships and understanding of these as "childlike" - non normative in some ways
Relationships as different/ Lack of reciprocity	Is this reciprocated by the girls? Sarah I would say sort of. Jane probably just thinks "haha, yeah George whatever". So yeah I will see that it is mostly one-sided-ish. It's not an agreed I'm your girlfriend you're my boyfriend kind of thing.	Lack of reciprocity in relationship. Suggests that for an interaction to count as a relationship there needs to be a formal agreement
Mothers as facilitators	So would they go out at all together? Sarah and with yeah they would go out, but that would be facilitated by the parents, we will take them out and they would play bowling. We've got bowling for instance, I'm quite friends with Sarah's mum now because of this. So we've going bowling we've gone to the cinema for food, that sort of thing. We've gone to the house and then come to ours for parties, birthday parties and that sort of thing. So it's very much like a childish, you know George couldn't, I don't know about Sarah, Sarah might manage because she's a bit more high-functioning than George.	Mums as facilitators of romantic life Going out and engaging in activities that would resemble dates but all facilitated by mums
Going on dates		
Low independent functioning as a barrier		Romantic interactions as "childlike"
Going on dates independently impossible		Low functioning as an influencing factor
On-going maternal involvement	But George couldn't go out on a date as such and be left alone with her even in a restaurant. He would need to be supervised even if it was a case of them sitting in one table and us sitting in another. You couldn't be left there while we got a coffee or something for an hour. He couldn't do that because something could set him off because of his autism. Something that	Limited autonomy/ inability to go on dates independently Supervision required- significant maternal involvement by being physically present Sense of disappointment in participant's voice?

Autism traits and triggers as a barrier	you can't foresee could happen and that could set him off, so she couldn't be left alone. So it's not a proper relationship even in a friendship type of way, you know to go with a friend for coffee or something. He couldn't manage that unsupervised.	Autism triggers as a barrier
Relationship as not "proper"	And you mentioned his autism playing a part in this?	Not a "proper" relationship
	Yes.	
	So what could set him off?	
Maternal involvement as necessary	Oh anything, like someone bringing in a guide dog. George is petrified of dogs. Somebody just saying the wrong thing to him or sometimes he just remembers something that happened and it can set him off. And once triggered you has phrases that he uses but I know he's upset and you need to settle him down. Other folk wouldn't realise that because it's not I'm upset (...) It's strange phrases he uses but I know he's upset he needs calmed down and I need to maybe remove him from the situation so yeah.	Mum as the only person that knows his triggers and ways of communicating distress. Potential romantic partner would need to be able to do the same?
	So have you found that you've had quite a big role in supporting such relationships for George?	His difficulty communicating distress/ self-regulating as barrier to relationships
Making it happen	Yeah it wouldn't happen without me and the girl's mum. I just wouldn't happen so yeah. I said I don't know about Sarah so much if she would be able to go out with friends on her own but certainly George absolutely could not. With support he can do things, he goes out during the day with his day centre where there's maybe 3:1. And he manages that okay but he couldn't just be totally...	Without maternal input from both sides it wouldn't happen
Additional support as necessary		Significant amount of support would be necessary due to poor independent functioning
Low independent functioning as a barrier	Yeah. In terms of barriers that could be in terms of developing relationships, I know you mentioned one of them would be his difficulty to do that independently, is there any other barriers you can think of?	
Limited understanding of what relationships require	I think because of his autism he wouldn't really understand what is required in a relationship. Again a very Primary School kind of way if he sees it that you're his girlfriend then you're his girlfriend's and I don't think you could quite comprehend why you wouldn't want to be. You know as with your average neuro-typical person, if they liked someone and they asked them out, if they said no they would be ok she doesn't want to go out with me. But George would understand that "why would you not?", you know. I'm your boyfriend and that's it, end of so there's not that comprehension	Not understanding what is required in a relationship
Limited understanding of social rules such as reciprocity		Not understanding reciprocity of interest as a requirement/ social rules governing relationships
		Difficulty dealing with romantic interest not being reciprocated? How are these emotions managed?

	there really.	
Romantic interest present	Even with that definition of a relationship and with that lack of understanding, do you think that George would want a relationship, does he want a girlfriend? Have you had such conversations?	Interest in females and romantic attraction evident through having a "type"
Questioning if romantic intent is real	George is not a big chatter. I think he understands that there are boys and there's girls and that he wants a girlfriend. And he's obviously attracted to females because he seems to like certain things like the girls that he says he loves there's common features. So he obviously has a type that he liked but I don't think he fully understands what that means, not really. I don't know, it's hard to say because he doesn't speak about things like that, he'll just state in a very matter-of-fact way I love Sarah, Sarah is my girlfriend. Regardless of what Sarah thinks about this (laughs). I don't know it's a hard one. But we've never had a conversation about beyond that sort of level of conversation, about boyfriends and girlfriends, relationships, sex anything like that.	But still this doesn't feel like genuine romantic intent due to poor understanding and matter of fact thinking?
Lack of conversations on sex and relationships	Would this be a conversation he might initiate?	Never had a conversation about romantic and sexual needs. Surprising given that he expressed interest but shows limited understanding?
Conversations not initiated by son	No George doesn't really do conversation, it is very much statements of fact. Facts as he sees it, whether it's a fact or not and he's very repetitive in how he speaks he would repeat things over and over and over. If I've heard a lot of Sarah ones I've heard that thousands of times. That's not an exaggeration.	Conversations not initiated by son. Perception of him as perhaps unable to hold a meaningful conversation?
Romantic interest and attraction as normal/normative	And how would you feel about the possibility of George being in a relationship of that sort?	
Hope he can achieve relationships in future	I think it's nice. I think it's nice that he feels, I mean he's in his twenties. When you're in your twenties you would like to have a girlfriend, you would like to be in a relationship.	Being in relationships as the norm and what one should aim for at that age. Sense of disappointment in her voice- perhaps reflecting sense of loss?
Commitment to facilitating relationships	I think that if you can manage it and whatever level makes him happy then it's good enough to help facilitate that. At whatever level he can manage, as long as my only worry is that he can be in your face, you know. Some girls have found him quite over bearing. And he's not doing anything really bad but you want to sit right next to her and smile at her and look at her and she's like "right I've had enough". And he does not understand that I'm liking this but Jane is not too keen.	Hope that he can manage it at whatever level- acceptance this might differ from the normative level? Desire to continue facilitating
Fear of male becoming overbearing		Worry about being "in your face"- difficulty understanding boundaries and personal space especially when romantic interest not reciprocated